

# disability now

your rights, your voice, your life

## Olympic trials

The Paralympic dilemma

# Stephen Fry

## Proud to be bipolar



£2.80 Issue 10

August 2008

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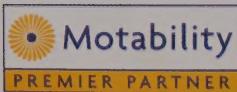
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## NEWSSTAND DISTRIBUTION

If you have problems obtaining *Disability Now* through your newsagent or supermarket, visit <http://availability.mmcltd.co.uk> for the nearest stockist or call MMC on 01483 211 222

## ALTERNATIVE FORMATS

*Disability Now* is also available on cassette, disk or via email from Talking Newspaper Enterprises  
Tel: 01435 862 737; [www.tnauk.org.uk](http://www.tnauk.org.uk)

Published by Scope, a registered charity, no 208231.

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The views expressed in *Disability Now* are not necessarily those of Scope, the editor or staff.

Printed and distributed by Engage Group.

[www.engagegroup.co.uk](http://www.engagegroup.co.uk)

ISSN 0958-4676

The magazine has been printed on recycled, FSC-certified paper.



20,735  
1/7/06 - 30/6/07



# editorial

## Why we're right on hate

A reader recently berated *Disability Now* among other things for the fact that we've majored quite heavily on hate crime. Our time, he said, would have been better spent auditing the state of the NHS on its 60th birthday. There are a number of points to make in response. The first is that audits of the NHS at 60 were to be had anywhere in the media, whereas the reduction on appeal of the sentences of the three men who killed Brent Martin hardly registered on the mainstream news agenda. The only place where the shock and outrage of disabled people found a voice was on our website and in this magazine.

**“Hate crime continues to be a clear and present danger for disabled people”**

Another consideration is to do with the use by disabled people of the NHS. Our state of health may or may not be related to our primary impairment.

Therefore many of us use the NHS in the same way and for the same reasons as anyone else. What might well be interesting would be people's accounts of the disablism treatment (by which I don't mean medical interventions) they've received at the hands of NHS professionals. But I suspect this is not what our critic had in mind.

Meanwhile, hate crime continues to be a clear and present danger for disabled people. In addition to distressing cases such as the murders of Brent Martin and Stephen Hoskin, together with the disgraceful treatment of Christine Lakinski, people are subject to much lower level abuse and harassment on a daily basis for no other reason than that they are disabled. That's why we'll continue to encourage disabled people to report what they regard as hate crime as such, the police to listen and investigate accordingly and judges to impose sentences which reflect that these are crimes motivated by hate and prejudice.

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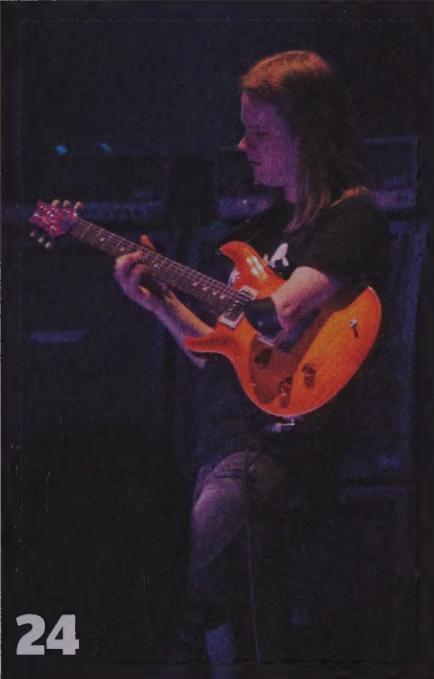
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# the new Ford Galaxy Liberty Range

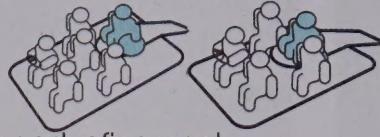
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# newsview

# The lift now arriving at...

**Paul Carter**

In four years to the month, the eyes of the world will be on London as the Olympic and Paralympic Games come to the capital.

Many millions of pounds are currently being spent on expanding and improving London's transport system to cope with the 500,000 spectators the Olympic Delivery Authority (ODA) expects to use the network on the busiest days of the games.

But how will these plans benefit disabled people?

"We want to create a legacy before the games even happen," says Hugh Sumner (*pictured*), transport director for the ODA.

"Many plans, such as the redevelopment of Stratford station [the main terminus for the Olympic Park] will be completed by 2010, two years before the games."

He also talks about a wish to have the 2012 Games leave a "soft legacy" of things such as greater public faith in accessible transport.

"We're aiming to create a real step-change in London and across the country by renewing confidence in public transport," he says.

In spite of that, it is clear



**Breaking through the glass ceiling:** Hugh Sumner, the ODA's transport director, at the new St Pancras International station

that not even the Olympic Games has the power or the budget to transform London's underground system into a fully accessible network in only a few years.

With this in mind, an important aspect of the Accessible Transport Strategy\*, published in May, appears to be around the concept of "multi-modal transport" – where various modes of public transport are combined in one journey for the most accessible route.

This involves integrating services such as Dial-a-Ride, taxi and bus services into one. But how would that work in the case of someone wanting to get to

the Olympic Park from, say, Putney, in south-west London, where the nearest District line tube stations only have steps.

"In that scenario," says Mark Todd, the ODA's disability adviser and himself a disabled person, "we would suggest that they drive to Richmond station, where there will be blue badge parking provision, and from there by London overground direct to Stratford."

Despite the 550 blue badge spaces at the Olympic Park, Todd says they want to encourage disabled people to travel by public transport rather than by car, requiring

that every visitor receive personalised, accessible journey information.

There are some proposals included in the strategy that are remarkably ambitious, such as looking at introducing passenger-operated, retractable ramps into some trains; similar to those on buses, by 2012.

"We have an opportunity to use the power of the Games to make real changes for disabled people," says Todd. "I think it's far better that we make 70 hard-to-reach proposals and only hit half of them than make 10 easily achievable proposals and deliver them all."

Sumner is enthusiastic about his plans, though not unaware of the scale of the challenge facing him and his team, conceding that delivering all aspects will be "a hell of a challenge".

Whether they succeed in that challenge will depend greatly on how many of the proposals make it off the drawing board and, in turn, how successful they prove in getting disabled people to the Games. The world will be watching.

\*[www.london2012.com/documents/oda-transport-accessible-transport-strategy-accessible-pdf.pdf](http://www.london2012.com/documents/oda-transport-accessible-transport-strategy-accessible-pdf.pdf)

# breaking news

## RSPCA quizzed on pets

Katharine Quarmby

*Disability Now* has gathered evidence that Britain's best-known animal charity, the Royal Society for the Prevention of Cruelty to Animals (RSPCA), often prosecutes disabled people

for alleged animal welfare offences.

Many pet owners, in particular those with mental health problems, have been prosecuted. The effect of the trial and media coverage on them can be harrowing.



Dogs for the Disabled has launched a new project that partners children with autism and dogs. It takes two years to train an autism assistance dog. Six more dogs will be partnered with children this year and another eight in 2009. Seen here, William Johnson and his assistance dog, Percy.

The Crown Prosecution Service (CPS) tends not to prosecute disabled people. Its code for crown prosecutors states: "Crown prosecutors must balance the desirability of diverting a defendant who is suffering from significant mental or physical ill health with the need to safeguard the general public."

Mind's policy officer Anna Bird said that it was worrying that a "high" number of people with mental health problems appear to be being prosecuted by the RSPCA.

Lawrence Butterford, a pet owner and mental health nurse who has experienced mental distress, said: "I am saddened that the RSPCA cannot accept that pets can play an important role in keeping people with depression well...it sounds extreme to prosecute people with depression."

He added that animals must be protected from neglect but that prosecution was not the answer.

An RSPCA spokeswoman said that the charity did not target disabled people for prosecution but admitted that it did not keep statistics on how many defendants had impairments.

• See feature, pages 36-37

## As she lay dying



MARK LAKINSKI

Mark Lakinski, brother of Christine Lakinski (above), the disabled woman who was urinated on while she lay dying on her doorstep in Hartlepool last July, has given *Disability Now* a harrowing account of the last 16 minutes of her life.

His account will be used as the foreword to a major report on disability hate crime, produced by Scope, the UK Disabled People's Council and *Disability Now*, to be published this summer (see guest column, page 47).

He says that three of his sister's neighbours found her motionless on her doorstep. One neighbour was Anthony Anderson, who was getting ready to celebrate his birthday.

"These were her neighbours... However, Christine was disabled

and what happened next, I believe, was purely down to that fact."

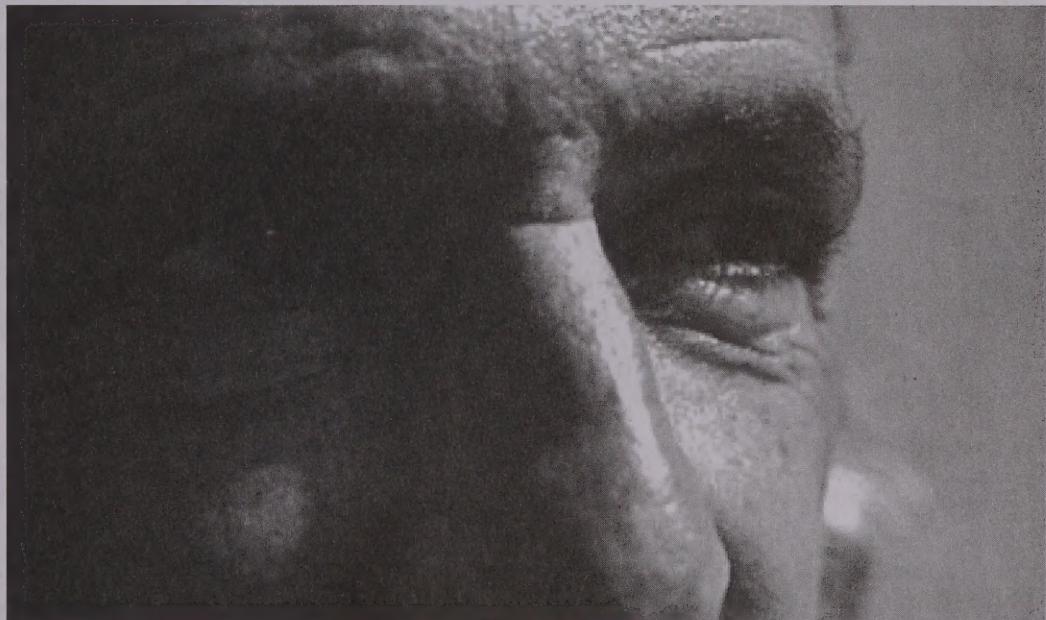
Mr Lakinski says that Anderson shouted: "I'll show you how to deal with her." "He then took centre stage for the next 16 minutes, applauded and egged on by the other two. It started with a kick to Christine's feet which got no response from her, so a bucket of water was produced from Birthday Boy's house and thrown over Christine, who did in fact groan and move slightly at this."

Then her attackers filmed their assault. "The final act was for Birthday Boy to pull back his towel and urinate all over Christine as she lay dying, all recorded on the mobile phone for later entertainment... She was left where she lay."

Mr Lakinski adds: "If an ambulance had been called, when Christine collapsed, she might have died with dignity and with pain relief in hospital and not on a dirty pavement, violated at the moment of her death by a braying bunch of louts who, I firmly believe, saw her as an easy target because she was disabled."

He concludes: "No mention of disability hate crime was ever brought up by officials dealing with this law case although Christine was visibly disabled."

# HIV loophole: no change



CRUSAID

## Katharine Quarby

The government has confirmed that it will not extend disability hate crime legislation to people living with HIV/AIDS.

The Disability Discrimination Act (DDA) already covers their condition but if they experience disability-targeted hate crimes, these are not treated as aggravated under Section 146 of the Criminal Justice Act.

Following talks with the National Aids Trust (NAT), Lord Fowler and Baroness Gould had tabled an amendment to the criminal justice and immigration bill, to give people with HIV equal hate crime protection.

The amendment was not

accepted by the Ministry of Justice. A spokesman told *Disability Now*: "We believe those with HIV-positive status who would not specifically be caught by section 146 are now protected by other sections of the Criminal Justice Act, as are other minority groups who are not specifically mentioned."

But HIV hate crime exists. In one case, John (above) came to the organisation Crusaid for help after his HIV status and home address were exposed when a card was put up in a shop window, saying he was an AIDS carrier. A few days later he got home from work to find two men in his flat. They beat him with chair legs and he ended up in hospital for six days.

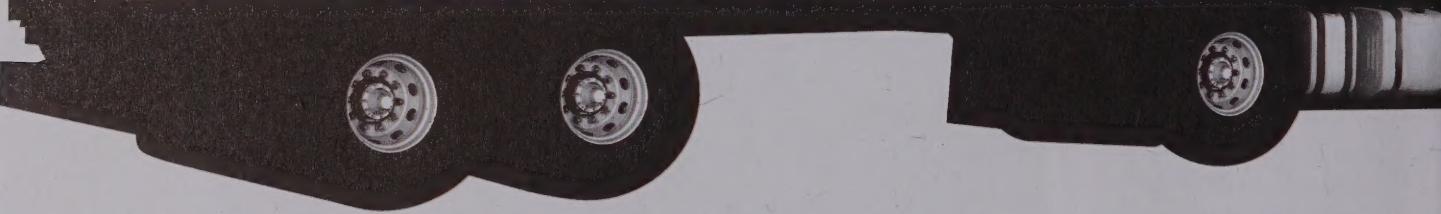
Deborah Jack, head of NAT, told *Disability Now*: "The government needs to send out a strong message that HIV-related hate crime is unacceptable by changing the law to ensure people with HIV are given the same protection as others."

Andrew Little, a member of the Metropolitan Police's disability independent advisory group, said that the response from the Ministry of Justice was "disappointing".

"People with HIV, already recognised as 'disabled' under DDA 2005, need to know that hate crime will be taken seriously, recorded and monitored, investigated and prosecuted appropriately," he said.



# “The Low Emission Zone has started”



The Low Emission Zone (LEZ) covers most of Greater London and operates 24 hours a day, 7 days a week, every day of the year. Diesel-engined lorries over 12 tonnes are now affected, and from 7 July lorries between 3.5 – 12 tonnes will also be affected. These vehicles will need to meet the LEZ emissions standards of Euro III for particulate matter (PM) in order to be driven within the zone without having to pay the £200 daily charge.

## What you need to do

- If you plan to drive a diesel-engined vehicle within Greater London, check whether your vehicle meets the LEZ emissions standards.
- You can do this by referring to the table opposite, using the vehicle compliance checker online at [tfl.gov.uk/lezlondon](http://tfl.gov.uk/lezlondon) or calling us on 0845 607 0009.
- If you wish to avoid paying the daily charge, you have the following options: reorganise your fleet (so only vehicles that do meet the standards are driven within the zone), modify your vehicle by fitting approved pollution abatement equipment or upgrade to a newer vehicle.
- Operators of vehicles which do not meet the LEZ emissions standards are advised to take early action as options such as modifying a vehicle can take time to complete.
- If you have not taken action to meet the required emissions standards you will have to pay the daily £200 charge (for vehicles over 3.5 tonnes) to drive within the zone.
- You can pay this online at [tfl.gov.uk/lezlondon](http://tfl.gov.uk/lezlondon) or call 0845 607 0009 up to midnight on the first working day after travel. If you fail to pay this charge, you will be issued with a Penalty Charge Notice.
- All non-GB licensed vehicles (inc. Northern Ireland) which meet the emissions standards need to be registered with Transport for London. Registration forms are available online or call 0845 607 0009 or (+44) 20 7310 8998 from overseas.

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Vehicle type and definitions	Date affected	Required emissions standards
Heavier lorries. Heavy diesel-engined vehicles exceeding 12 tonnes Gross Vehicle Weight (GVW).	4 February 2008 Euro III for PM	From 4 February the LEZ emissions standard is Euro III for particulate matter (PM). Vehicles first registered as new with the DVLA on or after 1 October 2001 are assumed to meet this standard.
	3 January 2012 Euro IV for PM	
Lighter lorries. Heavy diesel-engined vehicles between 3.5 tonnes and 12 tonnes GVW.	7 July 2008 Euro III for PM	From 3 January 2012 the LEZ emissions standard will be raised to Euro IV for PM. Vehicles first registered as new with the DVLA on or after 1 October 2006 are assumed to meet this standard.
	3 January 2012 Euro IV for PM	
Large vans. Diesel-engined vehicles between 1.205 tonnes unladen and 3.5 tonnes GVW.	4 October 2010 Euro III for PM	From 4 October 2010 the LEZ emissions standard is Euro III for PM. Vehicles first registered as new with the DVLA on or after 1 January 2002 are assumed to meet this standard.
Some vehicles with Euro II engines and a very small number of vehicles with Euro I engines may also meet the required LEZ emissions standards of Euro III for PM. The list of eligible engines is available on our website or call us for more information. Cars and motorcycles will not be affected.		

or call 0845 607 0009

Transport for London



# newsroundup

## Cash gives voice to hope



The government announced a package worth over £50 million in an effort to improve services for children with communication needs.

It came as the Conservative MP John Bercow published a report into his review of the existing services for

children and young people with communication needs.

His report puts forward 40 recommendations aimed at ensuring that children with communication needs are identified at an early stage and receive better support.

Key recommendations

include a "communication champion" to drive delivery of reforms and improve local performance; better training for professionals; and research into improving the life chances of children with communication needs.

The government has accepted Mr Bercow's recommendations and will address them in an implementation plan in the autumn.

Pictured is Natalie Sides, who has been involved in Scope and BT's *No Voice, No Choice* campaign that helps people with communication impairments receive the equipment and support they need.

### Disability decision a 'huge setback'

Disability organisations and lawyers said that a decision made by the Law Lords – the highest UK court – was a huge setback for disability discrimination law.

The decision said in effect that a disabled person who made a mistake could not receive special protection based on their impairment and that they could not be discriminated against if the other party did not know they were disabled.

The Lords found that the

Borough of Lewisham, in London, did not discriminate when it evicted a man with schizophrenia for subletting his council house, because the borough would have treated any other tenant in the same way. The man said he had only sublet the flat because he stopped taking his medication.

The Equality and Human Rights Commission said the judgement "seriously undermined" the recognition that avoiding discrimination sometimes demands that disabled people are

treated differently.

Disabled lawyer Eleanor Williams, who specialises in discrimination for the firm Darwin Gray and is a director of the Discrimination Lawyers' Association, said that it was a "hugely important" ruling and she believed the Lords had got their decision wrong.

"By bringing disability into line with other discrimination law, the House of Lords was saying that disability was simply a fact, like being a woman or being black, whereas it actually affects your whole life."

### Court win after beauty visit turns ugly

Visage Hair and Beauty, a beauty salon in Southall, west London, settled a disability discrimination suit with three disabled teens.

Amy Fox, Aruna Gill and Jemimah Kumba, the latter two of whom are wheelchair-users, wanted to get their nails painted.

But an employee is said to have told the girls: "This is my shop. There isn't enough room for the pushchairs."

Amy Fox, who has learning difficulties, said the three friends had been extremely upset by what happened. "I thought it was very unfair and it was not very nice of them to do that to us."

A Scope spokesman said: "Disabled people are entitled to the same treatment as everyone else and it is important that those who do suffer this sort of treatment have the courage to speak out."

The beauty salon owner, Parmail Kaur, denied the allegation that the teenagers were turned away because they were disabled, but settled out of court, paying the teenagers £4,500 in compensation.

She said: "It was a health and safety issue. Our shop is very small and they didn't have an appointment. They are angry but it is all a misunderstanding."

## Campbell calls for portability now

The government has failed to commit itself firmly to enabling disabled people to move more easily between local authorities. Baroness [Jane] Campbell had tabled an amendment to the health and social care bill, which would have forced councils to ensure a smooth transition to an equivalent level of support (portability) when a person who receives a care package or direct payments moves to a new local authority.

She told the Lords: "The amendment proposes a practical solution to the intolerable injustice of being, as I am, almost a prisoner of one's local authority, unable to enjoy the same social and economic mobility and freedom of movement as our non-disabled counter-parts."

Baroness Thornton, for the government, said its new social care green paper would address whether care and support should be based on the principle of local flexibility or on national standards, where someone would be entitled to the same support no matter where they live.

Baroness Campbell withdrew her amendment but told fellow peers it was still difficult to "see light at the end of the tunnel".

## Equality proposals still full of holes

Campaigners said they were encouraged by new government proposals for an equality bill, to be introduced later this year, but insisted there were still gaps that needed plugging.

The bill will aim to bring nine separate anti-discrimination laws, including the Disability Discrimination Act, into a single piece of legislation.

Last year, the government provoked uproar when it said it would introduce a single equality duty in the bill, in place of the disability equality duty (DED).

The DED obliges public bodies to consider how their policies and practices will affect disabled people, while the single equality duty would only require authorities to set equality objectives and take "proportionate" steps to achieve them, effectively allowing them to set their own agenda.

Details of the new duty are not likely until later this year.

RADAR chief executive Liz Sayce welcomed some of the new proposals but said it was vital that the government did not weaken the existing public equality duties.



PICTURE COURTESY OF THE SCOTTISH PARLIAMENT

## Sign of things to come

Margaret Mitchell MSP (*above, right*), convener of the Scottish Parliament's equal opportunities committee, learns sign language from a pupil of Donaldson's School in Linlithgow. The committee was launching a report on the Scottish government's progress towards achieving equality for disabled people. The committee said it was "broadly content" with the government's progress.

## EU law will require 'substantial change'

Campaigners criticised proposed new European anti-discrimination laws they say are "unclear" and miss out areas of vital importance to disabled people.

The draft directive from the European Commission would provide protection from discrimination on the grounds of disability, age, sexual orientation, religion and belief in areas outside the workplace.

Discrimination at work is already protected under EU law.

European Disability Forum president Yannis Vardakastanis welcomed the "wide scope" of the proposal but said it was "unclear, too short and introduces significant restrictions of the right to equality for disabled people in several areas, such as education and insurance".

He said it would create "legal uncertainties" and "room for interpretation", while some provisions would contravene the UN Convention on the Rights of Persons with Disabilities.

He said the draft directive would need "substantial changes".

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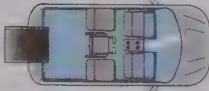
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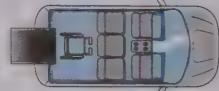
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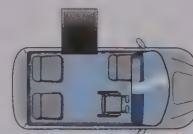
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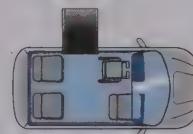
■ Rear Wheelchair Access



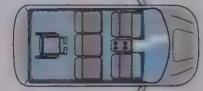
■ Rear Wheelchair Access



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■ Side Access  
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# campaigns

## Protesters target dopey drug laws

Disabled people who use cannabis to ease their conditions held a protest to complain at being criminalised. **Sunil Peck** reports

**S**ix years ago, Rebecca Gadsby (right) was on a cocktail of pills and painkillers, but was still in too much pain to be able to get out of bed. Then she started taking cannabis.

She says it has transformed her life, by stopping her muscle spasms and pain. "I was not the sort of person that had ever done any drugs, but I read up on it and found no problems with it."

On 25 June, Gadsby left home in the West Midlands at half-past two in the morning to attend a demonstration opposite Downing Street. Activists were calling on the government to change the law that makes it illegal for people to use cannabis for medicinal purposes.

The mood at the demonstration was relaxed, with joints rolled and smoked as the police looked on. A Metropolitan Police spokesman put the number of demonstrators at 30, and he said no arrests were made. Gadsby was in agony

during the demonstration but was too terrified to take any of the cannabis she had brought with her because of the police presence.

She said it was important to campaign for the right to cultivate cannabis for personal use because too many disabled people risk damaging their lungs with the sand, plastic and fibreglass that is often present in contaminated cannabis bought from street dealers.

A medicinal cannabis-user known as Pinky, who organised the demonstration, told *Disability Now* that he was fighting for people like his aunt, who is in pain because of multiple sclerosis, his sister, who has Alzheimer's, and people who go blind from glaucoma rather than risk a prison sentence for being convicted of possession of cannabis.

One protester, Chris Baldwin, said that, although the government needed to stop persecuting disabled people for using cannabis, the media was fuelling



KELLY MULLAN

public ignorance of the drug with its negative coverage.

One recreational user from Southampton told us that he attended the demonstration to show solidarity with medicinal cannabis-users, who he thought had a "strong case" for legalisation.

Another protester, Winston Matthews, urged medicinal users like himself to defy an "unjust law" by cultivating cannabis for personal use.

When we asked Pinky for his message to the Prime Minister, he said: "None of the people in your cabinet have any of our conditions. [You are not] in our shoes, where your life is unbearable and you are looking to

euthanasia to ease your pain and suffering and discomfort, [so] please come to us and listen to us."

Pinky delivered a petition to Number 10 calling on the government to legalise the use of medical cannabis to ease spasms and pain if their doctor has stated they have symptoms that can be alleviated by cannabis.

A Home Office spokesman declined *Disability Now's* request for a response to what the demonstrators had told us. Instead, he re-iterated that the government had no intention of legalising cannabis in its raw form for medicinal use.

### → Contact us

- phone us 020 7619 7323
- write to us **Disability Now, 6 Market Road, London N7 9PW**
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)

# If nine become one



As the government tries to bring anti-discrimination law under the one umbrella of the single equality bill, **Ian Macrae** finds differing degrees of support

It would be easy to imagine that the divergence of views on the rightness or otherwise of the government's goal of bringing nine pieces of anti-discrimination legislation together via a single equality bill would split according to whether the views were held by disabled or non-disabled people.

This turns out not to be the case.

The single equality approach finds support across the divide, with highly-placed and influential disabled people including Baroness Campbell of Surbiton and Lord Low of Dalston both in the "content" lobby, siding with

such government figures as women and equality minister Harriet Harman and her junior minister Barbara Follett.

Ms Follett (*pictured, right*) told *Disability Now* that the government wants to simplify and tidy up existing legislation.

"Our main aim is to de-clutter the current legislation: nine acts, numerous small bills and two-and-a-half-thousand pages of guidance. We want to make it easier for people to know what their rights are."

In terms of the benefits Ms Follett sees a single equality act bringing, she says: "We're going to try to

make it more straightforward to show that you're disabled. Under the DDA, you have to prove your disability and the single equality bill intends to repeal that."

There are disabled people who view the new approach with suspicion, even trepidation, however, and at least one of them is a big hitter.

Sir Bert Massie (*pictured, left*) is the former chair of the Disability Rights Commission, one of the regulatory bodies replaced by the Equality and Human Rights Commission (EHRC) last year. Now a member of the EHRC's disability

**By setting up the EHRC first, the government put the cart before the horse. And now the cart and the horse are on totally separate roads**

committee, he accepts that the proposed new act is now necessary, but criticises the way it came about. In short,

he thinks that things were done in the wrong order.

"By setting up the EHRC first, [the government] put the cart before the horse. And now the cart and the horse are on totally separate roads."

He feels there should have been a thoroughgoing review to assess and establish the precise needs of disabled people in terms of the equality agenda. That review would have then informed the way any new bill was framed.

In response to disabled people's concerns that we continue to lag behind in the equality stakes and therefore require discrete rights legislation and protection, Barbara Follett tries to be reassuring.

"We'll try to strengthen rather than weaken the situation for disabled people. We'll just make sure that what you've got you keep."

Whether such assurances will allay the concerns of activists like Sir Bert remains to be seen. He at least continues to worry that the responsibility for framing the future of disability equality rests with people who may not know just what we need.

## → Have your say

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# media watch

## Model meets role model

Is it good television having disabled people fighting it out for a magazine photo spread? **Emma Bowler** has been watching the TV series that sought to match disability with the fashion trade

BBC Three's *Britain's Missing Top Model* [BMTM] seems to have hit the mark.

For starters it's so rare to see disabled people on TV that just having disabled women on the screen is enormously refreshing – let alone the fact that they are openly discussing disability, being catty, wooing judges and looking beautiful.

The fact that the series involves well-known names in the world of fashion also gives it credibility. There's industry expert Jonathan Phang, who helped launch the careers of Jodie Kidd and Naomi Campbell; Wayne Hemingway, co-founder of fashion label Red or Dead and Hemingway Design; Marie O'Riordan, editor of *Marie Claire* magazine; Mark Summers, casting director; and Lara Masters, disabled actor, presenter and writer.

Beauty is very much the name of the *BMTM* game, as contestant Jessica says. "I wanted to be on this show because I want people to go, 'Wow, you can be disabled and do that, you can be disabled and pretty.'"

Lara Masters adds: "I'm sure there will be a backlash from disabled people complaining about the show being elitist but the industry is elitist and disability has no role at present. We were trying to change that."

It affected Jonathan Phang, the contestants' mentor. "I'm embarrassed at what I used to think. What I thought was the epitome of beauty is ludicrous really. Who was I to judge and why shouldn't I have considered disabled girls to be beautiful?"

Will *BMTM* give us the result we want? Wayne Hemingway says: "I thought



**The industry is elitist and disability has no role. We were trying to change that.**

the girl that won had guts but there was another whom I preferred. I think she would have probably done more towards highlighting attitudes towards disability. But it's like football. I always want the underdog to win!"

The winner may have been chosen more for her looks than for her ability to be a disabled role model too. That's disappointing but when you are dealing with an industry that, as Hemingway puts it, is "morally bankrupt", it's going to take more than a six-part series to change all that. At least the series has the potential to change the opinions of viewers, which could be a winning result in itself.

## AD awareness up

The broadcasting regulator Ofcom has published the results of its research into awareness of audio description (AD) services on TV. AD adds an extra voice to

soundtracks to convey information on action and expressions to sight-impaired viewers.

The research followed an awareness-raising campaign involving 16 broadcasters and the RNIB and featured

awareness-raising promos broadcast throughout February and March.

It showed that among people with a visual impairment, awareness is up from 43 to 72 per cent since the campaign began. Among the

general population, it's up from 37 to 60 per cent.

Ofcom has also concluded that the best way to drive up audio description usage will be by making it available on more shows. We can only say hear, hear!



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# disabilityrights

## Speaking up for children

**Nathan Giles** became the youngest person to speak at a formal UN meeting when he helped present a report on children's rights. Here he explains why the government should start listening to disabled children like him

In June, I went to the United Nations in Geneva to help present a report written by the Children's Rights Alliance for England (CRAE) to the UN Committee on the Rights of the Child.

Each country that is signed up to the UN Convention on the Rights of the Child is investigated by the committee every five years. This year, it is the UK's turn.

For the last year, I have been working as a children's rights investigator with CRAE, finding out how children feel about living in England today. Our team compiled surveys and interviewed groups of children, who included disabled children.

Our findings showed there is still discrimination and stereotyping due to disability, which is often not helped by media portrayals. Disabled children, particularly those with learning difficulties, were worried about getting access to information, and wanted better support for their families with things such as house adaptations. They were also concerned about getting enough help to live on their own in the future.



**Sign of the times:** Nathan (centre, front) and other CRAE members in Geneva

Bullying in school was a big issue for all children, including disabled children. Access to leisure facilities was also a problem, with children having to travel a long way to take part.

Our report included recommendations that we hoped the UN committee would ask the UK government to take action on.

We asked for disabled children to be more involved in making decisions about their lives, for more support for families, and better access to information in general and about the UN convention. We also called for guidelines to help the

media improve the way it portrays children and avoid stereotyping them. We asked for more support for bullied children, particularly in schools, and for the needs of disabled children to be taken into account when deciding what activities are available at youth and leisure centres.

I was chosen, by the other delegates, to speak at the pre-sessional formal meeting of the committee. This is a very serious meeting, but I had prepared my speech so I wasn't too nervous.

After speeches by all the voluntary organisations and the children's commissioners

for England, Scotland, Wales and Northern Ireland, the committee asked us questions. These questions are confidential, but I hope what I said will have an impact.

There is a long way to go before the rights of disabled children are fully recognised, but hopefully, when the committee produces its concluding observations in October, we will be able to start asking the UK government to make changes.

I had a great time in Geneva, and feel very proud that I am the youngest person ever to speak at a formal UN meeting, especially as a disabled person.

## New Nepal builds new hope

For centuries, Nepal has ignored disabled people. Activist **Shudarson Subedi** hopes rights can be built in from the ground up in the world's newest democracy



DHRC NEPAL

Shudarson Subedi, speaking, with other disability activists at a protest in Nepal

**T**here is no accurate current data on the prevalence of disability in Nepal and the statistics that are available do not reflect the range of disabilities.

In particular, mental illness in Nepal is still not appropriately categorised and many mentally ill people are sent to prison.

Historically, disability movements have only been present in Nepal for the past 40 years and for about 26 years only four

organisations existed.

This was largely due to the strict rules surrounding the setting up and running of organisations that needed authority from the royal palace.

After the restoration of democracy in 1991, non-government organisations mushroomed. Strength of pressure from Nepal's disability movement began to raise awareness and make disabled people and our issues more visible.

Today there are positive initiatives in place for the development of disabled people's rights. The government of Nepal and

**Most Nepalese believe that having disabled children is a punishment for something in a previous life**

national and international disability organisations are working in the field and there

are now major advances in special education, inclusive education, advocacy awareness and human rights, even though most of the programmes are only limited to urban areas.

A major concern in Nepal is that disability is still not recognised as part of the development agenda and mainstreaming process.

National, international, government and non-government organisations are focusing on poor and marginalised communities such as women and lower-caste ethnicity minority groups, but very few organisations include disability issues in their policies.

The majority of Nepalese society believes that having disabled children is the result of a past fault or a punishment [for something] in a previous life. Parents feel severely burdened by having disabled children and prefer to send their children to an orphanage rather than keep them. The majority of disabled people are also excluded from primary-level education and health care, mainly due to the cost of treatment.

To overcome these problems, Nepal has developed special policies and legislation for disabled people, but sadly most of the provisions are

not being implemented and even within the provisions there remain discriminatory practices.

For example, in January 2008 the Nepal government signed up to the United Nations Convention on the Rights of Persons with Disabilities, but it has yet to ratify it.

Nepal has been restructuring its political system and in April the first members of the new Constituent Assembly were elected, following a peace agreement that ended 10 years of armed revolution in 2006.

After nearly 250 years, the rule of monarchy in Nepal has ended. Disabled people have played a key role and political parties have finally included disabled people's issues in their manifestos for the assembly.

However, only two disabled people were elected as an assembly member and one was nominated by the cabinet, from a total of 601.

But as a disability and human rights defender and being physically challenged myself, I am optimistic for the future.

- Shudarson Subedi is founder and president of the Nepal Disabled Human Rights Center, which is a partner organisation of the charity Disability and Development Partners

## Disabled refugees face serious problems

Many refugee camps cause severe problems for disabled refugees on a daily basis, according to the first major report to address the issue.

The Women's Commission for Refugee Women and Children said there were serious problems with the physical layout and infrastructure of refugee camps.

Many disabled refugees rarely leave their shelters and cannot take part in decision-making.

Refugees in urban areas are worse off than those in camps, with "virtually no-one" providing them with assistance.

The report added that people with learning difficulties face even greater discrimination and stigmatisation than those with physical and sensory impairments.

## China set to beat UK in ratifying UN convention

China is set to ratify the UN Convention on the Rights of Persons with Disabilities as it prepares to host the Beijing Paralympics.

In late June, the National People's Congress passed a bill submitted by the State Council, China's cabinet, that approved the country's ratification of the convention.



**David Obinna Anyaele, from Citizens with Disabilities, Nigeria, at the campaign launch in Beirut, Lebanon**

## Films to raise issue of war and disability

The UN has launched a campaign to raise awareness of the effect of war and violent conflict on disabled people and their human rights.

Hissa Al-Thani, the UN special rapporteur on disability, said it was vital to raise awareness of the relationship between war and disability, and of the

violation of disabled people's rights in war zones.

A series of short films, featuring disabled people in war-affected Bosnia, Iraq, Lebanon, Palestine and Yemen, will be used to raise awareness of the difficulties faced by disabled people in enjoying equal rights and access to services in areas of conflict.

The UK has yet to join the 29 countries that have so far ratified the convention.

## US discrimination bill will close gaps in work laws

Members of the US House of Representatives have overwhelmingly backed a new act that will make it easier for disabled people to prove they are victims of

discrimination at work.

The Americans with Disabilities Amendments Act will close gaps in the law that denied protection to people with conditions such as epilepsy and diabetes.

The US Senate is also expected to pass the bill. Although President Bush has expressed concern that it could lead to excessive legal action, he is thought unlikely to veto the bill.

# onetowatch

## Guitar idol

Guitarist Marc Playle featured in the finals of the Guitar Idol 2008 competition, where the judges praised his "epic 'traditional' rock soloing with class". Now 22, he has been playing since he was 14. He plays with Newcastle-based rock band Minnikin, and describes their sound as "melodic heavy rock with a twist of grunge". Minnikin's debut album, *Europa*, is due to be released later this summer.

### What's the best thing about being disabled?

I have never thought of myself as being disabled as I was born this way and have always overcome obstacles that have been thrown at me.

### What makes you angry?

Having hayfever, banging my head off things and guitar strings snapping!

### What's the funniest thing anyone's ever said to you about your impairment?

Would you have been left-handed if you had a left hand?

### How do you deal with people who barf on about your impairment? Have you any good putdowns?

People don't barf on about my impairment. I don't mind it, so other people don't make a deal of it.

### What's the one thing that could be invented to make your life as a disabled person better?

A self-stringing guitar.

### What do you most like about being a performer?

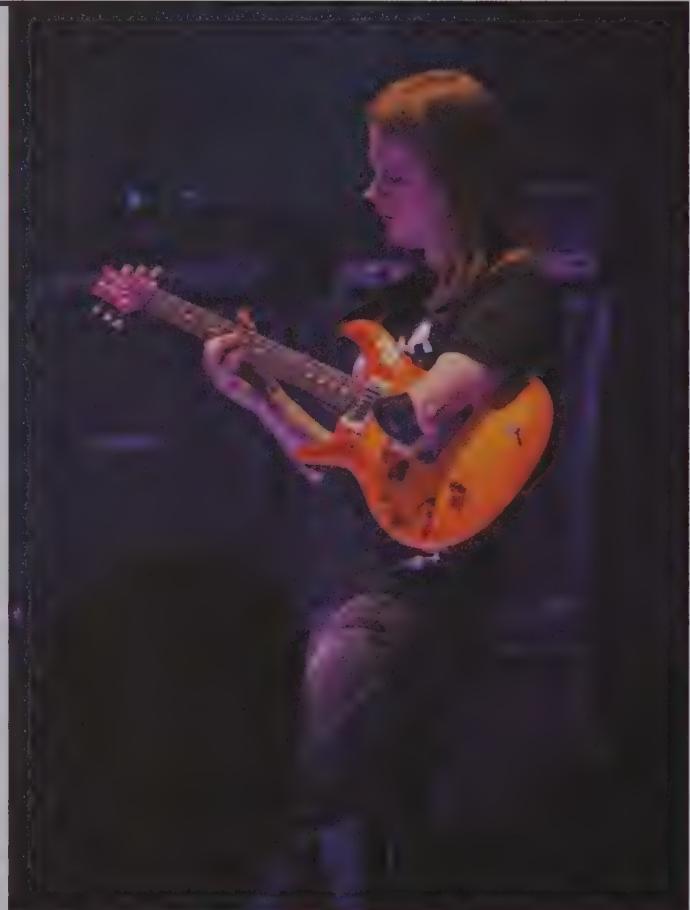
Playing in front of an appreciative audience on stage and people telling me I inspire them.

### And what do you not like about it?

Packing up the equipment at the end of a gig!

### Who's your favourite disabled person ever?

I don't really know any disabled famous people except for Rick Allen, the drummer from Def Leppard.



### Do you have any special or hidden talent apart from playing the guitar?

I can also play drums and keyboards.

### If you didn't have your impairment, which other one would you like to have?

I would not want any.

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### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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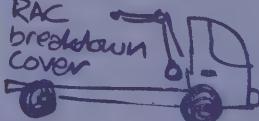
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# a little bit of **Stephen Fry**

The much-loved writer, actor and TV presenter Stephen Fry helped many other people with bipolar disorder 'come out' with a documentary about his condition. He tells **Sunil Peck** why he believes people with mental health problems should develop a sense of pride

**I**t is easy to see why Stephen Fry has been one of our most cherished celebrities for over 20 years. He can have an audience hooting with laughter at a bum-hole gag one second, then in silence a few words later with his account of the devastating effects mental illness can have in economically-deprived areas like the East End of London.

Fry was speaking at an event organised by the user-led mental health charity Stand to Reason, where he was publicising a book about recognising the signs of manic depression and ways of managing it\*.

Before rushing off after his speech, Fry spoke to *Disability Now* about his own bipolar disorder.

One thing he has talked openly about are his attempts to treat his depression with drugs and alcohol. So, I ask, would Fry have found a book like the one he was publicising useful?

"Definitely, I think anything like that would be useful. But I think particularly it's the knowledge that there are people you know around you who are comfortable with the

condition and are not ashamed of it, so you don't have to hide it."

Fry is passionate about the need for people with mental health problems to develop a sense of pride.

In a rallying cry to the people he jokingly referred to as maddies who crammed into a club to see him, he had said earlier: "There's a word that Stonewall [the gay rights organisation] and others used a great deal. It's used in an annual march in London, it's a word that was used by the African-Americans from Rosa Parks onwards when she first sat on that bus, and that word is 'pride'."

**It's the knowledge that there are people you know around you who are comfortable with the condition and are not ashamed of it, so you don't have to hide it**

Without pride, Fry continued, we would never reach a day when a person could chat about their mental health problems in polite conversation.

"Once that pride is there, once we all stand up and account for ourselves and not be ashamed of ourselves, then it makes the rest of the population realise two things. One, that we are just them but with something extra. And two, how close we are."

It's this pride, he tells *Disability Now* later, that will help banish the stigma people with mental health problems face from the rest of society. "To follow some of the examples of the gay and racial movements. Honesty from those affected and a refusal to be ashamed."

Fry's condition was diagnosed in 1995. He had been starring in a West End play but vanished after critical reviews. He contemplated suicide in London before resurfacing in Europe a few days later. The diagnosis was pivotal. As he said in his 2006 television documentary, which explored his experiences of his bipolar disorder, *The Secret Life of the Manic Depressive*: "I'd never heard the word before, but for the first time, at the age of 37, I had a diagnosis that explains the massive highs and miserable lows



**“The fact that Stephen Fry is so famous and so well-liked and so talented and intelligent was enormously moving and important for me and it was easier for me to hold my head up high afterwards.”**

JOHNNY BOYLAN

I've lived with all my life."

His career as an author, actor and comedian stretches back to the 1980s. By the time he was diagnosed in 1995, Fry had starred in the film *Peter's Friends*, and had roles in TV shows including *Blackadder*, *A Bit of Fry and Laurie* and *Jeeves and Wooster*. Nowadays, Fry hosts the BBC TV quiz show *QI*, has a technology column in the *Guardian* and produces podcasts to download from his own website. He has also penned

four novels and an autobiography, *Moab Is My Washpot*.

Chris Danes, who has bipolar disorder, was among the adoring crowd at the Stand to Reason event. Danes has admired Fry's work for years. But he says that his respect for him increased when he watched the documentary. For Danes, the programme went a long way to reducing the stigma around mental illness. His friends watched it too and began to ask questions about his

condition and the ways in which it affected him.

“The fact that Stephen Fry is so famous and so well-liked and so talented and intelligent was enormously moving and important for me and it was easier for me to hold my head up high afterwards,” says Danes.

Neil Tinning, patron of the user-led bipolar organisation Manic Depression Fellowship (MDF) and the official photographer for The Jam in the early 1980s, says the stigma of bipolar



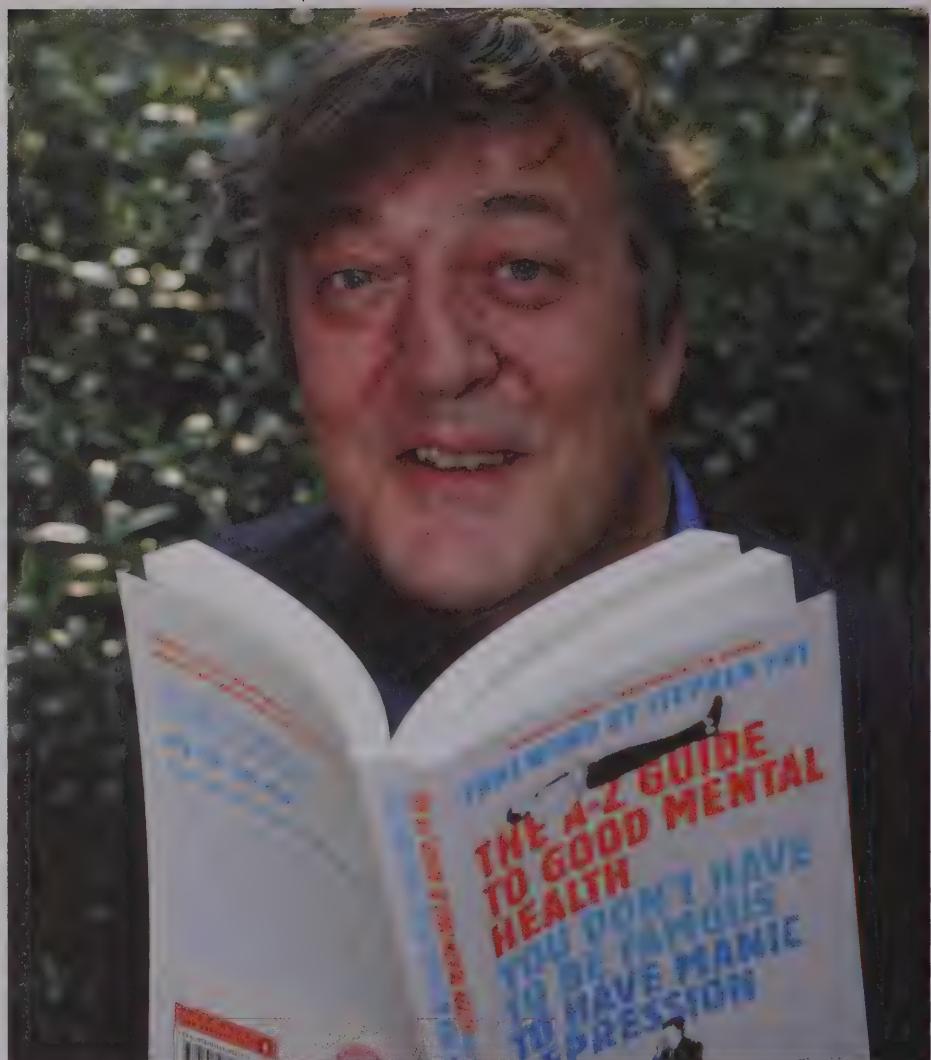
disorder still means that people with it are statistically more likely to attempt suicide than people with other mental illnesses. Nevertheless, Tinning says that Fry should be applauded for his courage in publicising his own experiences.

"Coming out with a mental illness can be a very difficult task. It can be even more difficult if you are a celebrity. Stephen has opened up some of the floodgates and I think we will get more people who will come out in the future because of what he has achieved."

Fry came out as gay before coming out as someone with mental health problems. So, as people jostled for an autograph and a hand-shake with Fry before he left the publicity event, I asked him whether he thought there were similarities between the stigma facing gay people and the stigma facing people with mental health problems.

"There are some things that are similar," he tells me. "People can get beaten up in parks for looking as if they have a mental health problem by cruel children and they can get beaten up in parks for looking gay. So there are similarities in the violence and contempt that the worst sections of society extend towards both classes of person, but there are obvious differences too. To call being gay a chronic condition would be quite wrong. You can have an immensely happy gay man that doesn't necessitate medication or isn't suddenly threatened by a mood change or an allergy or something like that in the way that mental conditions can be. But there are enough similarities to make the comparison valid I think."

Fry says his condition has been influential on his career, but he does not know to what degree. "Hard to



An open book: Stephen Fry at the book launch

quantify," he tells me later, "but probably a great deal. For good with creative splurges, for ill with black moods and creative blocks."

**Fry refers to his condition as an affliction, but one that he would not want to be rid of**

Although Fry holds up the civil and gay rights movements as shining examples of tackling stigma, and talks up the importance of collective pride, he does not feel that he belongs to a community of people with mental health problems. "No. No more than I belong to a community of gays, Jews, or asthmatics. Maybe that's just me."

Fry refers to his condition as an affliction, but one that he would not

want to be rid of. As he put it during his speech: "If you have a hundred people in a Stone Age village, you want some of them to stay in a cave boiling up the bones, some of them to go out and do the hunting. But somewhere you want one of them who is just a little off-kilter, whose ideas are just a bit weird, who has a creative imagination that is technically mad because he or she is suggesting doing things or trying things that no one has ever thought of before."

"It's actually necessary for our gene pool to have some people in it who are just not normal. It is an immense privilege to belong to a group of people who are not normal." ■

\*The A-Z Guide to Good Mental Health, by Jeremy Thomas and Dr Tony Hughes

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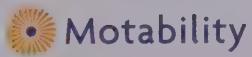
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# Games without frontiers

With more disabled athletes than ever before competing in this summer's Olympic Games, **Paul Carter** investigates the potential impact on the Paralympic movement

OSSUR

**W**hen the Olympic Games finally kick off in Beijing this summer, there remains the possibility that three disabled athletes could be competing side-by-side against their non-disabled counterparts.

South African swimmer Natalie du Toit has already qualified for the 10km open water event, while arm amputee Natalia Partyka will be representing Poland at table-tennis.

And as *Disability Now* went to press, Du Toit's compatriot Oscar Pistorius was still bidding to reach the qualifying time for the 400m, although it was looking increasingly unlikely he would make the grade in time, with his personal best still about a second outside the required "A" standard.

But Steffi Klein, a spokeswoman for

the International Paralympic Committee, the governing body of Paralympic sport, says this summer's disabled triumvirate will not be the first to compete at the Olympic Games.

"In the past, there have been some athletes with a physical disability who have competed in full-medal events within the Olympic Games," she says. "These athletes have been allowed to compete in the Olympic Games [within] the rules established by their international sport federations. We commend these athletes for their athleticism and ability to compete as they so choose."

Marla Runyan, who is blind, made it to the final of the 1,500 metres at the 2000 Olympics in Sydney, while Wilma Rudolph, who had polio as a child, won relay bronze way back in 1956 in

Melbourne, before going on to claim double gold in the 100m and 200m in Rome in 1960.

Despite these frontrunners of disability sport, it is the disabled athletes of today who have pushed Paralympic sport onto the mainstream news agenda, with both Pistorius and Du Toit taking up plenty of column inches in the build-up to the Games.

But their desire to compete alongside disabled athletes has not been met with universal approval, and their decision to compete outside the Paralympic movement has raised several issues.

The decision surrounding Pistorius's bid in particular has split both the disabled and non-disabled community.

Where Pistorius's situation differs from that of Du Toit and Partyka is that he →



GRAHAM BOOL PHOTOGRAPHY

### Dame Tanni: "It's still a very grey area."

relies on the use of prosthetic "blades" to compete, something the International Association of Athletics Federations (IAAF) refer to as "technical aids".

The IAAF initially banned Pistorius from competing in any of their events after a series of tests found that the prosthetics gave him "clear mechanical advantages", a decision that was later overturned by the Court of Arbitration for Sport (CAS).

IAAF spokesman Nick Davies is quick to point out that the decision was taken solely with the benefit of athletics in mind, and was not intended to lead to a ban on disabled athletes from competing.

"I think there is a misunderstanding about the IAAF's policy, since the issue was not really about disabled athletes, but about the use of technical aids which give athletes an advantage," he says. "If you consider the IAAF's record on disabled athletics – we were amongst the first to encourage Paralympic competition by hosting exhibition events for disabled [people] within the programmes of our own

events as far back as the 1980s.

"Also, disabled athletes, in particular Marla Runyon of the USA, who was legally blind, were allowed to compete in open competitions at the highest levels – IAAF World Champs and Olympics. She was a disabled athlete by every definition of the word. So the IAAF competition rules have nothing against disabled athletes – we only have something against athletes using what we consider to be technical aids."

Former British Olympic athlete Iwan Thomas, a former European and Commonwealth gold medallist over 400m, says he thinks classing prosthetics as technical aids is unfair. "I think he should be allowed to run. I don't think it's an issue," he says. "I know there have been studies and stuff, but I cannot see how not having any lower legs can give him any form of advantage."

Nick Davies says there is no doubt the CAS judgement "has opened the door". "We now have an obligation to ensure that, as technology improves, these prosthetics do not become a

MARK BAKER/AP/PA PHOTOS



form of 'techno-doping', he says.

Thomas, however, disagrees.

"Running spikes and things like that are improved all the time," he says. "I can see both points of view and I can understand the arguments, but for him to improve he has to look for the strongest competition he can. He has to go out and run against and train with non-disabled athletes to do that. I think he's achieved great things and, if he makes the South African squad, then I think he should be allowed to run."

Dame Tanni Grey Thompson is Britain's most successful Paralympian, and competed in five Paralympic



Games. She remains unconvinced of the benefits of allowing Pistorius in particular to compete, and called on the governing bodies to undertake more research.

"The authorities need to make a very clear, legally and morally sound decision. I think their initial ban was a bit rushed, but I think there needs to be more testing involved as to exactly what the advantages and disadvantages are, because at the moment it's still a very grey area."

The IPC, however, remains fully committed to Pistorius's cause. "As a Paralympic athlete, he is seeking a new competitive horizon and these

aspirations have propelled him into competition with some of the fastest athletes in the world.

"The IPC is highly supportive of Oscar's superb achievement as an elite athlete, an attribute he shares with many Paralympic athletes who compete at the highest levels of sporting excellence."

Ian Jones, a British athlete who competed against Pistorius at last year's Paralympic World Cup, adds: "I don't understand how people can shout at him and call him a cheater. I don't see how he can be a cheater when he hasn't got any legs. All he wants to do is better himself and do

the best he can.

"He's a good role model. I don't think he's devaluing the Paralympics in any way. He's just saying he thinks disabled people who are good enough to compete in the Olympics should be able to. He's said that he still wants to compete in the Paralympics and still wants to do both. I think it's absolutely brilliant."

For Du Toit (above), the road to the Olympics has seen far less controversy than that of her compatriot.

The fundamental difference is that she uses no form of prosthetics or aids to compete alongside non-disabled swimmers. In fact, the lack of a ➤



lower left leg puts her at an immediate physical disadvantage to her competitors.

Additionally, she is competing in a completely different event at the Olympics from the Paralympics, where she will still compete.

"We are immensely proud of Natalie, even though I don't think she recognises yet what she has done in global terms," says Moss Mashishi, president of the South African Sports Confederation and Olympic Committee. "She has set our country on the map and we have absolute confidence that she will do herself and South Africa justice in both events."

British swimmer Sascha Kindred welcomes Du Toit's dual qualification. "It's nice to see that Natalie is still taking the Paralympics very seriously and will still be competing," he says. "Natalie has always said that the Paralympics are her main aim, and that she wanted to see if she could qualify for the Olympics, and she's done that. It's not going to devalue the Paralympics.

"It's a good thing, because it gives us more media coverage and attention and shows that we are elite athletes, and that despite the fact she has a limb missing, she can compete against the very best."



**Top:** the main Beijing Olympics and Paralympics stadium. **Below:** Sascha Kindred: "Natalie can compete against the very best."

Dame Tanni points to a fundamental difference between the two athletes' respective sports.

"I think Natalie is OK because it's a disadvantage for her, but for Oscar, I'm not sure," she says. "Swimming is a very inclusive sport; everyone can train and compete in the same pool, but athletics is very different."

For many, the fundamental problem with disabled people competing in non-disabled events is the future impact this will have on the Paralympics.

Dame Tanni, Britain's most successful Paralympian, has concerns over the long-term effect that allowing disabled people to compete in the Olympics will have on the future of the Paralympics. "I don't want the Paralympics to turn into a B final," she

says. "It comes down to how the Paralympics are portrayed. There are a pile of people out there already who think that the Paralympics is secondary. People still say, 'Are you going to the main Olympics?' not 'the Olympics and Paralympics'.

"I have no issue with Oscar running at grand prix meets and so on, as Oscar will bring people into athletics. Oscar is a big story. It's just the long-term effect on the Paralympics that I have concerns about."

"I can totally understand that point of view," says Thomas, "but the fact is that he needs to run against the quickest athletes he can. He's already achieved great things in the Paralympics, and he's proved that he's head and shoulders above the competition there."

"I think the Paralympics are a great event, and I understand that some people might see it that way, but if he's going to improve and compete at the highest level, he needs to progress."

Klein says the Paralympics are a unique sport event for disabled athletes, with about 4,000 athletes from 145 countries participating in Beijing. "The growing media and spectator interest shows that people are interested in the Games and get inspired by the athletes," she says. "We do not see it as a B event." ■

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# Hounded

*Disability Now* has assembled evidence that Britain's best-known animal charity, the Royal Society for the Prevention of Cruelty to Animals (RSPCA), often prosecutes disabled people for alleged animal welfare offences. **Katharine Quarmby** reports

The prosecution record of the RSPCA, which as part of its remit investigates alleged animal cruelty offences, is causing concern to disabled people and mental health campaigners. Many cases have been highlighted to *Disability Now* by concerned solicitors, vets and disabled people themselves. Here is a small selection:

- In 2007, the owner of an animal sanctuary in Sunderland, Clifford Spedding, who had been prosecuted by the RSPCA for cruelty offences, had his suspended jail sentence lifted and his banning order for keeping animals rescinded on appeal. Allowing the appeal, Judge Peter Armstrong said: "The appellant began to suffer from depression and was simply unable to cope with a large number of animals and birds that had been dumped upon him," and he praised the work he had done over many years to protect animals.

- A nurse, Stephanie Greatorex, who had depression, was also prosecuted last year for causing unnecessary suffering to her dog. She is now receiving treatment for her depression but has been given a lifetime ban on keeping animals.

- The RSPCA prosecuted Rosalind Gregson for animal cruelty in 2005. Her son had just died, and Mrs Gregson had depression. At the time of her conviction, the RSPCA's prosecutor admitted: "It is not the prosecution's case that this defendant maliciously caused cruelty to the animals in her home, simply that she allowed her obsession to collect animals, as it were, to overwhelm her." Animal hoarding is recognised in the United States as a mental health

**The appellant began to suffer and was simply unable to cope with a large number of animals and birds that had been dumped upon him**

condition. Mrs Gregson was jailed for three months but was released on appeal. Judge Andrew Gilbart said that a community rehabilitation order was more suitable "as it would include counselling to help her deal with her grief" at the death of her son and her other mental health problems.

- The home of pensioner Betty McDiarmid, a 75-year-old wheelchair-

user with diabetes, was raided twice by the RSPCA. The first raid resulted in a local vet concluding that none of the animals were suffering. However, a couple of weeks later, the RSPCA deemed another raid necessary and brought in its own vet, who concluded that every one of Mrs McDiarmid's animals were suffering and should be seized. The RSPCA decided to prosecute, but the trial was halted when Mrs McDiarmid became too ill for it to proceed. She died soon after her trial.

Older people, too, lawyers say, are routinely prosecuted. Lawyers claim that many disabled and older people are prosecuted for neglect during short periods when they are unwell. Instead of being given extra support, they are prosecuted and their cases publicised in the press.

The RSPCA investigates animal cruelty offences. It is also one of a tiny handful of charities that launches private prosecutions. The Royal Society for the Protection of Birds used to carry out private prosecutions, but following criticism of its conduct as a prosecutor it ceased to do so and it now provides evidence to the Crown Prosecution Service (CPS). The

Scottish Society for the Prevention of Cruelty to Animals (Scottish SPCA) does not prosecute either – it hands over the cases which it investigates to the Procurator Fiscal's Office, the Scottish equivalent of the CPS. A Scottish SPCA spokeswoman says it works with disabled people and their support workers, in cases of possible neglect, to "improve conditions for the animal", and says that many disabled people "are excellent pet owners", such as Adrian Lynn (*pictured below*).

The CPS tends not to prosecute disabled people, unless the seriousness or other circumstances of the case demand it. Its code for Crown Prosecutors states: "A prosecution is less likely to be needed if [it] is likely to have a bad effect on the victim's physical or mental health, always bearing in mind the seriousness of the offence; the defendant is elderly, or is, or was at the time of the offence, suffering from mental or physical ill health, unless the offence is serious or there is a real possibility that it may be repeated... Crown prosecutors must balance the desirability of diverting a defendant who is suffering from significant mental or physical ill health with the need to safeguard the general public." Despite the RSPCA's claim that it "might not prosecute" in the case of a "defendant suffering from significant mental or physical ill health", *Disability Now's* investigation highlights many disabled defendants who were nonetheless prosecuted by the charity.

Most defendants in an RSPCA private prosecution are featured heavily in the press, on the internet and often on television. This coverage enables animal rights activists to take direct action against them. Such harassment can have a particularly significant effect on people



PETER DEVLIN PHOTOGRAPHY

**Top, Rachel Hurst; below, Adrian Lynn, who has diabetes, gave Pixie a new home after the dog was taken in by the Scottish SPCA. Pixie has saved Adrian's life on more than one occasion by alerting him when his blood sugar drops.**

experiencing mental distress.

Rachel Hurst, director of Disability Awareness in Action (*pictured left* with her miniature Schnauzer, Polly) says: "The RSPCA is prosecuting people who need help, rather than punishment, instead of those who are deliberately committing acts of cruelty." She adds: "If someone with a mental health condition cannot care for their animal they should not be prosecuted, but of course the pet should be protected."

Anna Bird, policy officer for Mind, says it is worrying that so many people with mental health problems appear to be being prosecuted by the RSPCA. "It is only right that if someone commits a crime that they are held to account, but when there are compelling underlying factors then this should be taken into consideration. People who are experiencing mental distress can be particularly vulnerable.

"The RSPCA should adopt a measured response in its handling of such cases."

An RSPCA spokeswoman says: "We certainly do not target disabled people for prosecution."

But she admits that the charity does not keep statistics regarding defendants' impairments.

"RSPCA inspectors receive comprehensive training on the Police and Criminal Evidence Act 1984 including the provisions relating to those who may be mentally disordered or otherwise mentally vulnerable... if in doubt they are treated as such and given the required legal protection. If we proceed to court it means the prosecutions department, which is separate from the inspectorate, has been satisfied with that process, and if the court has convicted, then so too have they." ■

# yourviews

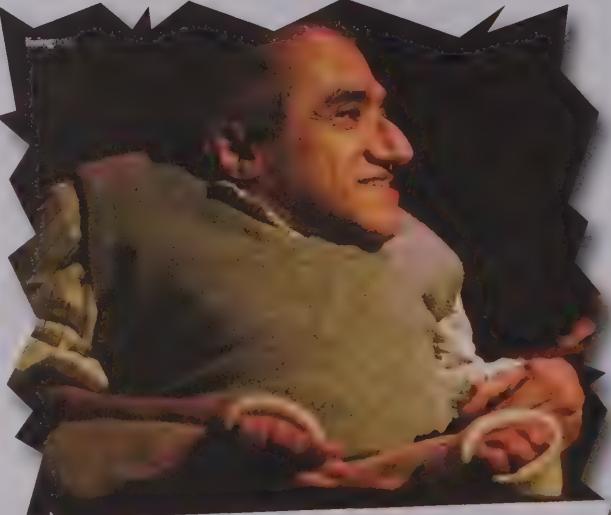
## Nabil Shaban: 'Garbage' or inspiration?

I want to comment on the interview with (your words) the "raging talent" that is Nabil Shaban (*Disability Now July, Playing Apart*). Below are two quotes of utter garbage that I feel are unworthy of *Disability Now*. "People don't care about the killing of disabled people. There is still an inherent prejudice towards us and a desire to see us removed from the face of the earth." And: "no-one wants to admit that at heart they are still Nazis." However, I agree with the implication that he is insane and the need for individuals to stand up to inequality wherever we see it.

*Disability Now* needs to get to the real issues: inaccessible transport and buildings, the postcode lottery for medical services and treatments, and inadequate support for families needing care support. You should have been looking at the NHS as it reached its 60th birthday rather than the ranting of a madman plugging his next play.

**Sean Kelly, by email**

I was very pleased to read Nabil Shaban's words about disabled people learning not to trust



## Playing apart

In the 1980s and 90s, actor, playwright, and filmmaker Nabil Shaban was in demand in film, TV and theatre. He played characters ranging from Hamlet, to a romantic lead, and a *Dr Who* baddie. Ten years on, the offers and commissions have dried up. In an outspoken interview with **Kathy Mullan**, he claims that creeping Nazi attitudes to disability are squeezing disabled people out of mainstream entertainment

people in authority, and that disability tends to foster a "rebellious nature". I felt like cheering when I read this. I myself am not disabled but both my sons are. My elder son has cerebral palsy and learning difficulties; my younger son has dyspraxia and Asperger's. I worry sometimes that I am too angry – but then think that anyone who has experienced our treatment by "professionals" would feel the same. My elder son was not diagnosed until he was two-and-a-half and I was told I was an over-anxious

mother and the reason he couldn't walk was delayed development due to his having been born prematurely. I was also told that my younger son had difficulties dressing himself because he was copying his older brother and that his "interesting" behaviour was due to my bad parenting! I'd like to say to all parents of disabled children and independent disabled adults: keep on being rebellious – it is the only way to change attitudes.

**Charlotte Fitzgerald, Ilford, Essex**

## New DLA form means more effort, less cash

I think Ms P Proctor from Birmingham should think again (*Disability Now July, Your Views*). I have had a form to complete under the government's "Right Payment Programme". It is the same form I completed for my original application for disability living allowance (DLA), except that it is now labelled DLA 300 and has a couple more questions. It is also now 40 pages long. This is obviously a complete reassessment of my claim. Most people will have had difficulties when they first applied (everyone I know did) and my first application was refused until I got help from social services. I was that told the new form was to check if I was still entitled to my claim and, if I was, to see if the amount could be reduced. Ms Proctor's MP may be correct in saying that the government is not contemplating scrapping DLA but it is certainly taking steps to reduce the amount paid. This is nothing but a weeding-out process. If the form is not filled in as the original one was, the claim will either be thrown out or, at best, reduced. By the time I have completed DLA 300 it will have cost me well over 100 working hours.

**Name and address supplied**

## Singer's wrong note

Miss G Cowley is entitled to her view of Peter Singer as someone who just wants to end the suffering of disabled babies (*Disability Now July, Your Views*) but this particular proposal is part of his publicly-avowed view of disability as a fate worse than death. Admittedly, he cites compassionate reasons for his recommendations but why does he not advocate better care and research into the causes of disability? Why death? In the 1930s, proponents of euthanasia advocated death as a compassionate measure for illnesses that can now be cured. If they had been allowed to have their way, it is unlikely such cures would have been developed.

**Ann Farmer, Woodford Green, Essex**

## Shining a light on loos

Reading your letters page (*Disability Now July, Your Views*), I thought I'd tell you of my limited use of accessible toilets. At a loo in Mullion, Cornwall, the light wasn't working and there were no windows so I had to leave the door ajar while my husband stood outside. At an inn in Devon, the loo seat was broken and when I told the manager, he said it had only happened the day before. At a pub in Somerset,

the accessible loo was used to store furniture. This is the full extent of my experience of accessible toilets. There must be many very good ones in this country. One day I hope to find one.

**Mrs A Crossman, Portbury, Bristol**

## Idea's a royal flush

Re: Flushed with success (*Disability Now July, Local Knowledge*). The use of ID cards for disabled people is a brilliant idea that all councils should take up.

**S Wyer, by email**

## Camden failed me too

Further to your article (*Disability Now July, Fighting for a Life*), I have also had problems getting basic services from Camden Council. I care for my 34-year-old son who has epilepsy and learning difficulties and I had less than two weeks' notice of my open-heart surgery. My GP called Camden social services and was told to apply for an assessment two weeks after I came out of hospital. Only after a report was prepared would an "appropriate" care package be offered. When I left hospital, I was meant to rest but had to go straight back to caring. Two days later, I was back in hospital with a heart attack. Currently, my heart works abnormally,



## Beyond Boundaries stretches limits

In response to your article (*Disability Now June, Media Watch*), I can't see why you are so negative about the *Beyond Boundaries* reality TV series involving disabled people (pictured, above). Surely each and every disabled person, along

with so-called disability organisations, are campaigning precisely for disabled people being able to go beyond boundaries which are set by society as a whole, and sometimes disability organisations themselves.

**Andrew James, by email**

probably because I have never been allowed to recover properly. Also, there is no disabled parking in our street. I have applied for a bay but Camden's traffic department keeps "losing" paperwork. Camden has a day care centre but won't take my son. They want to bus him across London instead. Unfortunately, they can't afford the transport! My son and I are listed at Camden as "under care". We get nothing!

**James Wild, London NW2**

## CLARIFICATION

In July, Laurence Clark wrote (*Disability Now, Disability Rights*) that disabled people on incapacity benefit or income support should be exempt from charges. Government guidance actually "usually" exempts people who receive only income support but no disability benefits and who have a net income not exceeding the "basic" income support level plus 25 per cent.

## Have your say

- write to us *Disability Now, 6 Market Road, London N7 9PW*
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# Our job, not theirs

The government is set to take over major decisions on how independent living is operated and regulated. That's not their job, says **Andy Rickell**, it's ours

**H**ow much should the government decide or regulate the building blocks of independent living, like direct payments, personal budgets, personal assistance and centres for independent living?

I worry that it might bring in rules that undermine the freedom that independent living should bring. Our voices must be heard before bad decisions are made.

Disabled people created the building blocks of independent living. Direct payments, the forerunners to personal budgets, were developed by disabled people; and centres for independent living were created by the grassroots activism of local disabled people in many communities.

They work because they respond to disabled people and our aspirations.

As independent living becomes government policy, the government is thinking about how to manage it. It may impose old-style ideas. For instance, the 21 criteria proposed by the government for good user-led centres

for independent living may become rules that decide which organisations get funding or recognition.

The government is also thinking about setting training standards for personal assistance, which presumably will then have to be checked and regulated. They may also impose financial limits on how much personal budget money can be paid to

## We have power as employers, power as customers and power as members and trustees of our own centres for independent living

personal assistants. I sense they want to regulate this.

I caricature the current regulation of disability services as one where one group of people (the government) tell another group of people (the regulator) to check how a third group of people (the service-providers) treat disabled people. This is

sadly inevitable because disabled people have no real strategic say in the delivery of disability services.

Contrast that with the power that disabled people have under independent living to decide how our services are delivered. We have power as employers through direct payments, power as customers through personal budgets and power as the members and trustees of our own user-led centres for independent living. Many of the checks and balances to ensure disabled people get a good deal from public funding are already in place.

We therefore don't need a heavy hand on the basics of independent living. In any case, those with the most to gain from making sure this works are disabled people. We would make the best regulators of the basics of independent living, helping individual disabled people get the best deal for every one of us.

One other concern is how the 21 criteria will be used by government. I can see them becoming the basis for getting grant funding, then for recognition (including the ability to win contracts) and then for how such bodies will be regulated. This would have massive implications for the survival and independence of some disabled people's bodies. Strong and independent bodies are key in the fight for equality and better independent living support. We should be leading the government's approach to user-led organisations and making sure we do not sleepwalk into letting government dictate who gets funding and for what.

Disabled people should have the leading role in all the processes and public bodies that decide how independent living is delivered and overseen. We need self-regulation, or rather, "user"-regulation.

## → Have your say

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# ask the experts

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## QUESTIONS AND ANSWERS

**Q** I am a 21-year-old man with cerebral palsy (cp) and am in a relationship with a young lady who also has cp. We wish to have intercourse but with our disabilities this is impossible to do alone. What are our options?

**Name and email address supplied**

**SP:** If you wanted assistance to go swimming or to the cinema with your girlfriend, there would be no real issue, other than the practical. But sex involves more than just practical issues, so first consider whether you and your lady friend would be comfortable being assisted by your support workers or personal assistants in such an intimate way. How relaxed would you be asking for such help and how would you raise the issue? The next question is whether the person who supports you is



ISOPRESS/REX FEATURES

willing to view your desire to have intercourse as a natural part of their role. Both issues are difficult and complex. They deal with people's feelings and moral attitudes about sexuality as well as society's and the caring professions' views and attitudes towards sexuality and disability. Some support workers feel they would be unsupported by managers or marginalised by colleagues. Obviously, you and your girlfriend shouldn't get too hung up on doing what others do or aim too high

too quickly. Most couples learn what works best by having fun and experimenting. Everyone is different and enjoys sexual intimacy in their own way. Exploring what suits both of you, together, is the first step. Penetrative sex might not turn out to be the best fun, especially if it involves a lot of effort, fatigue and involvement of others. This is something you might want to talk through with someone experienced and open, whom you both trust.

**Q** I receive disability living allowance and jobseeker's allowance because I had polio when I was two. I find it hard to use trains and buses and to walk for long distances. If I get a car through Motability, my chance of finding a job will increase but I need driving lessons and can't afford them. I'm 52 and Motability only provides financial help for people aged 16 to 24. Can any organisation offer me financial help?

**Marco Aurelio Santini, by email**

**EP:** Unfortunately, you've highlighted a significant gap in the assistance currently available now Motability has restricted grants for driving lessons to younger people. Motability's charitable funds assisted 2,240 people with the cost of driving lessons in 2007-2008 so they had little

## THE EXPERTS

### RELATIONSHIPS

#### SIMON PARRITT

Simon is a counselling psychologist who has studied psychosexual therapy. He was the only disabled director of the former Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD).



### FINANCE

#### DAVID CLARKE

David has spent 14 years in the banking industry and has worked for three leading financial service providers: HSBC, RBS and Clydesdale Bank. He is a senior partner with Clydesdale.



### PROPERTY

#### KATE SHEEHAN

Kate is a director of Years Ahead and an occupational therapist with 20 years' experience and a passionate interest in housing. Years Ahead works to meet the needs of the ageing population.



### EQUIPMENT

#### JOHN MANDRAK

John, who is blind, has worked in the disability sector for nearly 25 years as a disability journalist and consultant. He is an adviser on the Disabled Living Foundation's helpline.



choice but to ration in some way but I am not aware of any other national organisation that is filling the gap. The Department for Transport is looking at driving lessons for disabled people with stake-holders such as the Driving Standards Agency and the Forum of Mobility Centres. The focus is primarily on training for instructors and availability of adapted vehicles but it is also looking at whether training funds might be available to assist disabled people. Local charities may be potential source of funds and it would be worth contacting your local disability organisation, Citizens Advice Bureau or Council for Voluntary Service for a list of those that give individual grants to disabled people. Assistance to find charities which grant financial aid is available from Charity Search at [www.charitysearch.org.uk](http://www.charitysearch.org.uk) or tel: 0117 982 4060. Their free service is primarily for people over 65 but they may

consider requests from disabled people of 40 or over. The Forum of Mobility Centres' contact sheet, *Sources of Finance*, provides details on potential grants. Visit [www.mobility-centres.org.uk](http://www.mobility-centres.org.uk) or tel: 0800 559 3636.

**Q** I have reflex sympathetic dystrophy syndrome (RSDS), a painful disorder affecting the nerves, blood vessels, muscles, tendons and bones and, in later stages, the immune system, but my family does not believe me. My RSDS has been confirmed by several doctors but I have been banned from seeing my grandchildren with the excuse of, "Nanny's having one of her turns."

**Name and telephone number supplied**

**SP:** I am sorry to hear that you have such a tricky condition. Friends, relatives and regrettably even many in the medical profession

have great difficulty with conditions that present with symptoms such as pain and fatigue when there is no visual, obvious disability. People with chronic fatigue and ME will know all about this kind of prejudice. That said, I wonder if your family is refusing you access to your grandchildren for reasons that are more to do with what has gone on in the past. It is tempting for those around us, and indeed even us, to focus on the role disability and illness play when past relationship difficulties and conflicts lie at the root of things. Disability may sharpen these problems but may not be the main issue. Being disabled doesn't make us immune from all the other stresses and strains that affect relationships, be they

work, family or intimate. I suggest you talk to someone who can mediate between you and your family and try to address other issues that may lie behind your family effectively "banning" you from seeing your grandchildren.

**NEW PANELLIST:**



Gary Martin is welfare benefits supervisor at Walthamstow Citizens Advice Bureau. His main job involves resolving problems with disability benefits so they don't have to go to appeal. He has talked about Citizens Advice's work at many levels, including with MPs and members of the Lords.

→ If you have a question for our panel

- phone us 020 7619 7323
- write to us Disability Now, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)

**TRAVEL**

**ANDY WRIGHT**

Andy is a disabled travel industry professional with over 25 years' experience and is managing director of Accessible Travel, a specialist tour operator providing holidays for people with mobility impairments.

**MOTORING**

**ED PASSANT**

Ed is chief executive of the Forum of Mobility Centres, the umbrella body for 17 independent organisations which provide driver and passenger assessment for disabled people across the UK.



**LAW**

**ELEANOR WILLIAMS**

Eleanor is an employment lawyer specialising in discrimination at Darwin Gray. Disabled herself, she has a particular interest in disability discrimination. She lectures widely, and holds a number of advisory positions.

**LAW**

**DOUGLAS JOY**

Douglas is the senior solicitor at the Disability Law Service. He started working in community care and mental health law in 2002 and, as a blind person, has always had an interest in the rights of disabled people.

# backchat

## The word is still out

 According to the Oxford English Dictionary, you can be a victim of sexism, or racism, but not of ableism.

Apparently, the word is not important enough to merit inclusion among the more than half a million words in the "accepted authority on the evolution of the English language over the last millennium". Their words, not mine.

That's probably news to Amy Fox, Aruna Gill and Jemimah Kumba, the three

disabled teenagers, two of whom use wheelchairs, who were shooed away from a west London beauty salon because staff claimed there wasn't enough room "for the pushchairs".

If you can think of a better word to describe their experience than "ableism", Backchat would love to hear it.

The OED tells us that "ableism" is on its list of words for consideration, which apparently is "very large", but can't give any firm promises until the evidence has been "properly

assessed". Ironically, the word "ableist" entered the OED 15 years ago.

About time the OED realised that denying that the word is used is also a denial of ableism itself. Words matter.

## 'Care' minister keeps mum on fuel deaths

 Much optimism last December when social care minister Ivan Lewis told the Commons that the Department of Health (DH) recognised that fuel poverty was an important factor in contributing to poor health

and winter deaths among disabled people.

He promised to meet with Department for Work and Pensions (DWP) colleagues.

But despite two *Disability Now* Freedom of Information Act requests, the DH claims the meeting between Mr Lewis and disabled people's minister Anne McGuire on 3 April merely consisted of Ms McGuire asking for all future questions on the topic to be referred to the DWP. And that was it.

Glad to hear Mr Lewis was so vocal in making his point.



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E & O.E.

# guestcolumn

## Critical friends



As *Disability Now*, Scope and the United Kingdom's Disabled People's Council (UKDPC) prepare to publish a major report on disability hate crime, **Ruth Bashall** and **Anne Novis** (*pictured, left*), co-chairs of the Metropolitan Police's disability independent advisory group (DIAG), describe how their work is slowly helping the force improve its attitude to hate crime

**D**IAG is a diverse group of deaf and disabled people. Our role is to be a "critical friend" for the police: we advise when asked and relay concerns on issues such as communication with deaf people, disability hate crime, stop and search, domestic violence and how disabled people are treated by the police in emergencies and by custody officers.

We all share a passionate commitment to promoting the right to live free from violence and abuse with fair treatment from the police.

The Met has a big impact on disabled people. It is also a very bureaucratic organisation. Changing its practices takes time and determination. We have faced considerable barriers: some have made us

want to throw in the towel. And we still face a medical/special needs approach from many sections of the Met, in spite of its commitment to the social model.

But with the support of committed police people, things are changing, particularly in the case of disability hate crime.

Several of us had experienced hate crime but few had reported it. Disability hate crime was not recognised by the Met: if recorded, it was hidden in "abuse of vulnerable adults" statistics.

Then, six years ago, the UK's first disability hate crime "third party reporting site" and advocacy service was set up by Greenwich Association of Disabled People, which Anne then chaired. When Albert Adams,



a local disabled man, was murdered in 2005, Anne informed Greenwich police that disabled people thought it was a hate crime. The police disagreed but after DIAG pressure, the murder was at least recorded as a domestic violence murder.

DIAG has worked with some dedicated officers in the Met's violent crime directorate to ensure that disability hate crime is recognised, recorded, and dealt with seriously. A new recording system will start this autumn and we think it will better show the extent of disability hate crime across London.

Some DIAG members are working to make sure local police understand disability hate crime and deal better

with victims. We would like to see deaf and disabled people's groups also working with their local police on this, and police officers given disability equality training, including on hate crime and domestic violence.

Over the past year, after the murders of several disabled people across the UK, there has been increased awareness that disability hate crime is a real issue. We are now part of a growing online disability hate crime network.

DIAG has also assisted in writing the disability hate crime report (see above), which will be launched soon. We hope this leads to some responsive and positive action from the UK's criminal justice systems.

### → Have your say

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# upclose & personal

## Stop assuming, start listening

Author **Shanta Everington** has had a hidden impairment since she was a teenager. But she's still waiting for a little understanding



KELLY MULLAN

I'm not a wheelchair-user. I don't walk with crutches. Nor do I use a guide dog, white cane or hearing aid. I wasn't born with any bodily parts missing and I haven't lost any along the way.

Standing at five foot eight, in dress size 12-14, with brown hair and murky eyes, I'm just Mrs Average.

When I met my midwife for the first time, she ran through her standard questions and asked, "Are you disabled?" and answered, "No," without even looking up. It didn't exactly create the right environment to engage in a discussion about my disability. Because I do have one.

During my adolescence, I developed a condition called scoliosis, a lateral curvature of the spine. My spine is a

dramatic S shape. Heck, if you could straighten it, I'd probably be seven foot tall.

I call it a "hidden disability", because people don't generally see me as disabled. It's not that obvious if you look at me.

### You learn to accept yourself, although jokes about hunchbacks still make me flinch

From the front. With certain clothes on. But as the spine bends, the vertebrae twist and pull the ribcage round, which causes a rib hump at the back.

I certainly would have contested the word "hidden" when I was 15 and obsessing about my body and boys and everything else. You learn to

accept yourself, although jokes about hunchbacks still make me flinch.

Let's get one thing straight (poor choice of word). I don't have a bad back. Add headaches, neck and shoulder pain, RSI, cramp in the right hip and leg, not to mention the coccyx problem. On bad days, just about the only bit that doesn't hurt is my left leg.

A twisted spine pretty much affects everything else. According to celebrity nutritionist Dr Gillian McKeith, who also has scoliosis, my kidneys are having an awful time of it. I should be eating a lot more curly kale.

I'm not out for sympathy, just understanding. Once, on a training course, I requested a supportive chair facing the front, as sitting at an angle only

exacerbates my symptoms. I was met with a classroom-style plastic chair and was told there was only one comfy chair and a disabled person needed it. Er, hello?! I tried not to stare at the woman with the cushions as I pondered the hierarchy of disability and gave in to the pain that followed.

I subscribe to the social model of disability, that we are disabled not by our impairments but by society's inability to accommodate us. Yes, I am afflicted by pain, but if people would stop making assumptions about me and start listening to my needs, my life would get a whole lot easier.

- Shanta is the author of two disability-themed novels. Visit [www.shantaeverington.co.uk](http://www.shantaeverington.co.uk)
- See review, page 68



# Lara Masters: the fascinator

The presenter, model, milliner and judge on *Britain's Missing Top Model* reflects on reforming the fashion industry, disability politics... and hats

I don't buy fashion or gossip magazines because they perpetuate difficult standards for women to live up to. I love to look good but I don't follow fashion. I like to express myself but I don't like being sold something by a 13-year-old anorexic. It's my way of trying to have some principles.

If I was on *Britain's Next Top Model* I'd be buying into that. The reason I was a judge on *Britain's Missing Top Model* (BMTM) was to make a change to that industry: expanding the one-dimensional idea of beauty we're fed every day.

One day an overweight model with a facial disfigurement will be accepted, but we can't suddenly do that now; there'd be a backlash. The Dove ads have shown that more representative women can sell products; they don't need to use size zero 14-year-olds all the time. Again, it's a slow process and it's just starting. Subtle changes are needed before a disabled actor is selling you your cornflakes.

The fashion industry wouldn't be in business if we didn't buy the products sold by stick-thin, unhealthy girls. It's a collective responsibility: don't buy something that is sold in a way that's anathema to you.

Non-disabled people think I'm political but people who are political about disability

don't. Doing a reality TV programme about disabled models isn't politically correct from a disability politics point of view. But from an able-bodied person's point of view, I'm arguing for the winner to have a disability people can see – that's political.

I'm by no means hardcore, but we need to change the way disabled people are seen, and if we have to work from within the industry to do that, ie having disabled models, it's a viable way of changing things.

There's intolerance from some disabled people towards disabled people who want to work in the fashion industry. It's seen as a superficial aspiration, beneath them. But disabled people should be free to have the choice.

Disability needs familiarity. Even the contestants were nervous about meeting and living with other disabled people. Fear and prejudice around disability are so pervasive; even disabled people refer to other disabled people as "they". Hundreds of thousands are watching the series and having their ideas on disability challenged.

I was looking at ads in *Disability Now*: a lot of disability products are really useful and help me out, but the way we're so patronised by our ads – it's like we're expected to have lower standards in how we should

look. There's an ad for walking sticks to match your outfit. It's a good idea but the guy in the ad had his tummy sticking out in profile, with dodgy shoes, and the girl next to him wasn't styled nicely at all. It's typical of the way disabled people are seen. Ads for disability products don't have the same standards.

The more disabled I am, the more my clothes have to say something about me. People are going to have preconceptions, so if they see the 88 roses on my chair or my skull handbag or my butterfly tattoo, I influence how they see me.

I love burlesque: corsets, dramatic makeup, collars, hats with nets or flowers in my hair. I can go quite gothic and wear a lot of black and I can go punky or fetishy and wear a tight rubber jacket. I would never wear pastels or anything girly.

It upsets me that so many people think they can't wear a hat, but then they try one on and change their mind. I design and sell fascinator hats; wearing them, I get a really positive reaction. If I wear a hat to a club, I'm non-stop talked to all night.

If you're alive, celebrate! Don't save your best underwear for special occasions. Wear all your favourite clothes as often as possible. I wear my hats to Sainsbury's.

• Lara Masters was talking to Kelly Mullan

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# local knowledge



Pictured are (from left to right, all from Independus unless stated) Roy Emmerson, Mark Baggley (Choices and Rights), Robert Langford, Wendy Howard, Nigel Moody, Ray Newton, Valerie Burrows, Linda Cooper, Deirdre Edgar, Roger Jenkinson, Sue Lear, and Cara Nimmo and Mike O'Neil (both from North Yorkshire County Council)

A handful of user-led organisations have been given government money to secure their future. **John Pring** talked to two of them

**F**or at least two years, *Disability Now* has been reporting on the funding crisis facing centres for independent living (CILs).

Although the government has set a long-term target of a CIL in every local authority, many existing user-led groups have been facing deeply uncertain futures, saying their work is undervalued and their services under threat.

So when the government announced last year that it was spending £750,000 on supporting 12 user-led organisations to develop their long-term futures, it seemed like positive news, particularly when it was followed by the announcement of another £900,000 this June.

One of the 12 user-led groups to win funding from the initial £750,000 pot was the well-established user-led organisation Choices

and Rights Disability Coalition, in Hull. Choices and Rights had submitted a joint bid with Independus, which was formed from two small user-led groups in Richmondshire and Hambleton, north Yorkshire. They were given £100,000.

The aim was for Choices and Rights to mentor Independus as it moved from being a small group of disabled people who held social meetings and dealt mainly with access issues, to a more professional set-up, with a written constitution and paid members of staff.

The two groups have now been working together since April.

Choices and Rights chair Mark Baggley says he and his colleagues have been acting as mentors, encouraging Independus, rather than dictating how it should do things. "They needed some support and guidance. It's

been about us saying, 'This is what we did; this is where we went wrong.'"

Independus has already acquired office space in a leisure centre, bought office equipment and convinced a local pub to improve access so members could hold meetings there.

Baggley says it is "absolutely crucial" to develop organisations like Independus, so they can provide information, and offer disabled people jobs. "Any user-led organisation can do that, and be a voice for disabled people. If we can help educate organisations as they either form or strengthen, and that can be repeated across the country,

that can be a vital tool."

Independus chair Robert Langford says many of the issues they will focus on in what is a large, rural, sparsely-populated area, will be around isolation and public transport, and the inaccessibility of Victorian buildings. Awareness-raising will also be key, as will providing support to those on direct payments.

"I hope we can make them aware of what their rights and entitlements to services are," he says, "and support them in obtaining those services."

He says the money has meant a cultural change for his fellow members.

"It's been a bit of a rollercoaster ride," he says. "There was an awful lot to do and there still is."

## → CONTACT US

Do you know of an innovative, small-scale, pilot project, ideally one run by disabled people themselves?

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# Joining the Canadian club

A trip to the Rocky Mountains might not seem the most accessible holiday, but **Kathy Longley** was delighted to find easy access in the heart of the Canadian wilderness

**M**y initial sighting of the Canadian Rockies simply rendered me speechless; not a common occurrence, I can assure you. I stared awestruck at the majestic, snow-capped mountains arising from vast expanses of lush, coniferous forests, interspersed with vivid, emerald green lakes and meandering rivers. It was breathtaking, and I could understand why, to the native inhabitants, the Stoney tribe, these mountains were sacred places. I was filled with the eager desire of the 18th century European explorers to access this wilderness and experience all it had to offer. But how would I fare on wheels?

Fortunately, we had chosen the province of Alberta, not only the richest province in western Canada, due to its abundance of oil, but the one leading the way in making the Canadian wilderness accessible to all. I was delighted to discover many paved, well-maintained trails offering easy access into the depths of the wilderness and wheelchair-friendly bathroom facilities even in the remotest of carparks. The local people were friendly and welcoming and always ready to help wherever we went.

Our first destination was Kananaskis. In 1981, the Alberta provincial government funded the construction of William Watson Lodge, fully accessible accommodation designed specifically



PAUL IP

Water view: Kathy above Lake Louise

for people with disabilities. The facilities are basic but offer excellent accessibility, with each log cabin carefully designed to allow full access to wheelchair-users, with hoist facilities available in the bedroom and bathroom. The paved pathways within the complex have gravel on the sides to alert those with visual impairments, and Braille is printed on every sign. Shake awake alarms are provided, as well as books in large print and Braille, and a range of board games to keep you occupied in the evening.

The cost of the accommodation is heavily subsidised, with a one-bedroom cabin costing only \$30 (£15)

per night. The only real problem is securing a reservation. Local Albertans have first choice, and other visitors can't book until two months in advance, with reservations taken only by phone. Guests must bring their own bedding, which can be inconvenient if ➤

## Did you know?

Lake Louise is the highest village in Canada at 1,730 m (5,680 feet). The natives refer to Lake Louise as "the lake of little fishes", as the fish remain small due to the constantly cold temperatures.



## Why I had to have one...

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Patsy Watson



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PAUL IP

## High and mighty: on an accessible trail in the Rockies

you're travelling from abroad. But if you can get a reservation, it is well worth the effort. We managed to secure a five night stay and simply brought sleeping bags and pillows.

Once settled in, I was keen to explore, but with 18 km of accessible trails direct from the lodge, it was hard to know in which direction to head first. As it was late in the day, we opted for the short one km stroll down to Lower Kananaskis Lake to admire the views and look for wildlife. You certainly don't have to be much of an explorer to spot the Canadian wildlife; simply driving along the highway you will encounter deer, elk and Bighorn sheep. If you spot a few cars pulled over by the side of the road

then it is worth slowing down, as it just might be a bear sighting. These enthralling creatures are irresistible, but the Canadian authorities are working hard to educate tourists about the dangers of bear spotting. In the summer

**If you spot a few cars pulled over by the side of the road then it is worth slowing down, as it just might be a bear sighting**

months of July and August, when tourists come here in droves, a bear sighting can cause a major traffic jam. Regular encounters can habituate the bears to human presence, making them less fearful and more likely to enter built-up areas and become a threat.

One safe place to spot bears is the Peter Lougheed information bureau, just down the road from the lodge. As well as a dedicated bear-spotting

lounge, there are maps of all the accessible trails, Braille on all displayed items, and audiovisual commentaries on Canadian history, wildlife and the environment, far surpassing any of the museums on offer in nearby Banff.

Banff is the place to head to enjoy panoramic views over the Rockies, with a gondola to whisk you up to the top of Sulphur Mountain (2,281m). Access, though, is mediocre. A portable ramp means you can easily load a wheelchair into the gondola, but once at the summit you are restricted to a small observation platform, as other areas are dominated by steps and so completely inaccessible.

Banff's thermal springs, which are fully accessible, will help you recover from the chill at the summit. Discovered in 1883 by railway workers working on the lower slopes of Sulphur Mountain, the springs were opened to bathers in the 1930s. The complex has been fully renovated, with modern amenities

## Did you know?

The coast-to-coast TransCanada Highway, completed in 1970, is the world's third longest national roadway, at 7,821 km (4,860 miles).



including full disabled access, and offers the opportunity to luxuriate in waters of 39.9 degrees centigrade.

One sight you can't miss is Lake Louise. The first European to gaze on its beauty was Tom Wilson in 1882. He was so struck by its vivid green colour that he named it Emerald Lake, only for it to be renamed Lake Louise several years later in honour of Princess Louise Caroline Alberta, the sixth child of Queen Victoria. Turn up early or in the late afternoon to avoid the crowds or you will be jostling for position to take that memorable snapshot. There is a flat, accessible two km trail along the shoreline and the opportunity to go kayaking, although the exorbitant fee of £20 per half hour may deter you!

If you fancy something to get the adrenaline pumping, head to Kicking Horse River to experience white water rafting. The company, Hydra, allowed myself and my partner to do a "mild" run (with class I-III rapids) together, after which I got out and he continued into the class IV rapids. I must admit, the safety brief half scared me to death as the guide described in a rather bored, monotone voice all the things that could possibly go wrong. However, before I could ponder my looming death in detail we were kitted out in wetsuits, life jackets and helmets and ushered down to the rafts. Having been assisted into the raft, I perched on the edge as instructed, gripping my

### Did you know?

The lakes in the Rockies gain their vivid green colour from the light reflecting off the fine rock particles deposited into the lakes by the grinding glaciers. The particles absorb all the light apart from turquoise and vivid blue, which is reflected back into our eyes.



**Lake placid: Kathy kayaking in Yoho National Park**

paddle. To take part you need to be able to swim, paddle and be prepared to sign all your rights away through a comprehensive waiver.

The ride began sedately with the raft floating placidly, allowing time to reabsorb the safety briefing and to chat to my companions. But once we hit the class III rapids the adrenaline kicked in as the raft lurched and crashed through the waves, with glacial water drenching us from head to foot as we hung on to the safety ropes. My guide had oars, giving him more control to guide the raft round boulders and fallen trees, which was just as well as my paddling wasn't up to much. Soaking wet and rather sore, but fully exhilarated, I was helped out of the raft and driven back to base for dry clothes and a spot of lunch while my companions continued down the river.

Hydra is happy to accommodate anyone with a disability wherever possible, providing they have carers with them. The guides will spend more time explaining the safety procedures to those with visual impairments and allow those with hearing impediments to be placed near the guide so they can lipread. It's an awesome experience and well worth getting wet for! ■

### Travel Tips

**Flights:** flights from London Heathrow to Calgary, about a 1.5 hour drive from Kananaskis, cost around £500

**Time of year to travel:** spring and autumn are the best times to visit to avoid the summer crowds. Always take warm clothes and waterproofs whenever you go, as mountain weather is very unpredictable.

**Accessible accommodation:**  
William Watson Lodge: tel: 001 403 591 7227, office opening hours Monday to Friday, 8.30am to 4pm  
Banff Town and Lake Louise village hostels, £12-40 per night, [www.hihostels.ca](http://www.hihostels.ca)

Delta Lodge in Kananaskis, doubles £100-250, [www.deltalodgeatkananaskis.ca](http://www.deltalodgeatkananaskis.ca)

Fairmont Hotels at Banff and Lake Louise, doubles £125-450, [www.fairmont.com](http://www.fairmont.com)

**Useful Websites:**  
[www.parks.gov.ab.ca/kananaskis](http://www.parks.gov.ab.ca/kananaskis)  
[www.banffgondola.com](http://www.banffgondola.com)  
[www.raftbanff.com](http://www.raftbanff.com) (Hydra)  
[www.hotsprings.ca](http://www.hotsprings.ca)

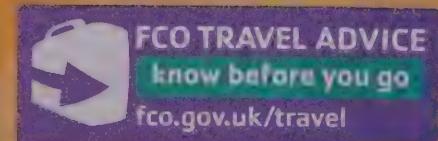
# Before you make tracks...



## Get the facts

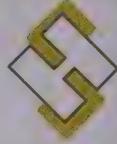
The Foreign & Commonwealth Office has produced a leaflet offering guidance for all disabled travellers going abroad.

To order a leaflet or download in PDF format  
visit [www.fco.gov.uk/travel/publications](http://www.fco.gov.uk/travel/publications)





# Sussex Health Care



Sussex Health Care is an award winning group of care homes that were founded in 1985.

Sussex Health Care now operate 15 care homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision as well as care for older people.

## In 2008 the group are developing 2 new purpose built facilities

Beechcroft Care Centre, West Hoathly Road, East Grinstead  
and

Hornastle Care Centre, Plawhatch Lane, Sharphorne, East Grinstead

**Beechcroft Care Centre**, which opened in May 2008, is in East Grinstead and caters for ten young people with physical disabilities and learning difficulties. Person-centered planning is at the forefront of our philosophy with the service users' needs and wishes at the centre of our service.



This care home provides specialist nursing care and is equipped with the latest technology aids to provide a safe, comfortable, homely environment for our service users. **Beechcroft Care Centre** is a specialist care home with ten places for people with learning and/or physical disabilities.

It offers superb purpose-built facilities with track hoisting throughout. Each single room is provided with en suite facilities. A swimming pool and spa pool are available to all service users along with sensory and physiotherapy rooms.



### Hornastle Care Centre, Plawhatch Lane, Sharphorne, East Grinstead

This service is due to open in August 2008. It will provide a purpose built residential service with 24 hour nursing support for people with acquired brain injury and neurological conditions.

#### Sussex Health Care operates the following award winning care homes:

BEECHCROFT CARE CENTRE (Physically Disabled & Learning Difficulties) East Grinstead 01342 300499

BEECH LODGE (Physically Disabled & Learning Difficulties) Broadbridge Heath, Horsham 01403 791725

CLEMSFOLD HOUSE (EMI) Broadbridge Heath, Horsham 01403 790312

FOREST LODGE (EMI) Nutley, Nr Uckfield 01825 712514

HORNCastle HOUSE (Adult Care) Sharphorne 01342 810219

KINGSMEAD CARE CENTRE (Adult Care & Physically Disabled) Horsham 01403 265335

KINGSMEAD LODGE (Physically Disabled & Learning Difficulties) Horsham 01403 211790

LONGFIELD MANOR (Adult Care) Billingshurst 01403 786832

NORFOLK LODGE (Learning Difficulties) Horsham 01403 218879

ORCHARD LODGE (Physically Disabled & Learning Difficulties) Warnham 01403 242278

RAPKYNS CARE HOME (Adult Care) Broadbridge Heath, Horsham 01403 265096

RAPKYNS CARE CENTRE (Physically Disabled & Learning Difficulties), Broadbridge Heath, Horsham 01403 276756

UPPER MEAD (Adult Care & Medical Conditions) Henfield 01273 492870

WHITE LODGE (Learning Difficulties) Purley, Croydon 020 8763 2586

WISTERIA LODGE (Physically Disabled & Learning Difficulties) Nutley, Nr. Uckfield 01825 714080

#### For further information

Please contact Corrine Wallace, Head of Operational Services and Future Development

Tel: 01403 217338 • Fax: 01403 210424

email: [corrine.wallace@sussexhealthcare.org](mailto:corrine.wallace@sussexhealthcare.org)



INVESTOR IN PEOPLE



# tried & tested

## Putting access to Britain in your pocket

If you're looking for somewhere to chill out or take the children this summer, a new pocket guide has a host of accessible suggestions. Ian Macrae has looked through it and visited one of its recommendations

Remember all those old gags with bad-taste punch-lines about the thinnest books in the world? Well now there's a genuine contender. *The Rough Guide to Accessible Britain* may be thin because so many visitor attractions aren't accessible. But to be fair, it's only in its first year of publication.

From city parks to theme parks and scenic journeys to coastal attractions, the guide boasts "over a hundred inspirational places to visit and things to do". That's not a lot.

The *Rough Guide* brand is well established and this addition to its list has been published in association with Motability Operations, the company that operates the car schemes for disabled people.

**Legoland has a positive attitude to disability that's reflected in the staff's can-do attitude**

Divided into sections, it features short entries on, for instance, historic cities and towns like Durham,



Pitlochry and Portmeirion, along with descriptions of attractions as diverse as Fountains Abbey and Thorpe Park. Each entry is headed with a row of symbols indicating which elements in a variety of access provisions are available. These include accessible toilets, parking, facilities for visually-impaired people and hearing loops.

Armed with the *Guide* and my two youngest children, Scott (7) and AmyBeth (11), we headed for one of the places listed as good for families: Legoland Windsor.

Although the *Guide* gave a good overview, for more detailed information I'd advise looking at the park's own leaflet for disabled



visitors. From this, but not from the guide, for example, you learn that most of the rides are only accessible to wheelchair-users who can leave their chairs.

The *Guide* rightly says that "Legoland has a positive attitude to disability that's reflected...in the staff's can-do attitude". My two, who aren't disabled, were desperate to try the newest water ride, the Vikings' River Splash, and there was absolutely no fuss about my getting assistance on to the ride, just a matter-of-fact attitude by the person who was supervising entry.

If you're put off by the possibility of spending most of your day waiting in a queue, don't be. As the

*Guide* and the Legoland leaflet both explain, there are a number of dodges for disabled people for avoiding queues. They've also instituted "Queue-bots", a new way of using a little hand-held device to prebook your next ride for a specific time slot. Indeed, this information was so new it hadn't made it into the *Guide*.

### INFORMATION

Costing £6.99 (including post and packing) or £1.99 if you're a blue badge holder, the guide is available by phone on 0800 953 7070 or from [www.accessibleguide.co.uk](http://www.accessibleguide.co.uk). It is also available in PDF on request



## Manchester's explosive charge

© TRANSPORT FOR LONDON 2005

Manchester may have followed London in announcing a congestion charge, but don't assume it will offer disabled people an exemption, says **Helen Smith**



**I**t always amazes me that so many disabled people assume that they will automatically be exempt from congestion charges.

At June's Mobility Roadshow, I was manning the stand for Mobilise, where I am director of policy and campaigns. This

gave me an opportunity to ask show visitors if they had concerns about Manchester announcing that it will be introducing a congestion charge.

Many people were of the view that since blue badge-holders don't have to pay the charge in London, they

will not have to pay anywhere else. However, the only reason that all blue badge-holders are exempt from the London congestion charge is that Mobilise campaigned successfully for a complete exemption. Without intervention, it's likely that blue badge-holders would have been liable to pay up to £40 a week just to use their cars in the capital. But just because this exemption was granted in London, it doesn't mean that it will be the same for other towns and cities that introduce a congestion charge.

It concerns me that the government is happy to leave the decision on who should qualify for an exemption up to local councils. When Mobilise chairman Douglas Campbell and I met with transport minister Rosie Winterton earlier this year to push for a national exemption from all congestion charging for blue badge-holders, this was refused. We were told: "Local councils understand the transport needs of local blue badge-holders and so it should be left for them to make the decision."

Mobilise strongly believes that the decision on exemptions should be made at government level, and we are campaigning hard on this principle.

When the charge is introduced in Manchester in

2013, motorists can expect to pay up to a total of £5 a day at peak times for crossing the M60 and a second ring around the city centre.

When I contacted AGMA (the Association of Greater

**It concerns me that the government is happy to leave the decision up to local councils**

Manchester Authorities) to find out whether disabled people will be exempt from the charge or not, I was told: "It has been proposed that blue badge-holders are granted a 100 per cent discount from the congestion charge currently being considered in Greater Manchester. We are waiting for the Department for Transport's current review of policy guidance to be complete before confirming the number of exemptions available for each blue badge-holder."

So, although it looks like there will be an exemption in Manchester, nothing has yet been confirmed! I therefore urge everyone to join Mobilise's campaign for a national exemption. It's possible the next city to bring in congestion charging may not exempt blue badge-holders, and that next city could be yours. • [www.mobilise.info](http://www.mobilise.info)



# A brand apart

The Mercedes B-Class is stylish, sleek and extremely well-built, but you'll pay for the badge, says **Paul Carter**

It seems that many car manufacturers are keen to steer clear of the MPV label. Mercedes are no exception, calling their B-Class a "compact sports tourer".

Despite having little to suggest anything sports-like, even at first glance the B-Class is unmistakeably a Mercedes. From the outside, the design is stylish and surprisingly sleek for a relatively big vehicle, while the interior of the cabin is well put together with an above average range of features as standard.

A good quality CD system is easily operable, and all buttons and switches have been thoughtfully placed for ease of access.

The seating is firm without being uncomfortable, and

offers a pleasantly high driving position.

It should also be noted how quiet it is inside the cabin, with very little noise coming through either from the road or from the engine, even at higher speed.

As with similar vehicles in the class, the floor of the car is fairly high off the ground, which is something that

should be considered when thinking about transfers.

Otherwise, it is exceptionally roomy with a good amount of storage, and plenty of extra legroom available.

Out on the open road, the B-Class excelled at higher speeds and in the upper gear ranges, though it did feel surprisingly light around



some of the sharper bends for a car of its size, which may not be a good thing if the car is likely to be used mainly for inner-city journeys.

In terms of performance, the car has enough under the bonnet to provide a decent level of acceleration, feeling responsive and punchy on the straights.

As you might expect from a brand such as Mercedes, the B-Class is an extremely well built, solid, all-round vehicle, with a decent range of features. As you may also expect from a brand such as Mercedes, you are likely to pay more than for similar vehicles in the class.

With competition in the market for similar vehicles extremely fierce, and with many of the B-Class's less expensive counterparts proving equally capable in terms of performance, whether you feel it is a reasonable price to pay ultimately depends on how much value you place in the badge on the front.

**The Mercedes B-Class is available on the Motability scheme in both petrol and diesel models, with either manual or automatic transmissions across the range. Prices range from an advance of £3,471 for the 1.5 litre manual, up to £8,280 for the 2.0 litre diesel automatic.**

## Cyclists and rowers named

Two more sports have announced their squads to compete at the 2008 Paralympic Games in Beijing.

In cycling, one of GB's biggest medal hopes at the games, 10 athletes were named, including reigning Paralympic champions Darren Kenny and Aileen McGlynn, along with former Paralympic swimming champions Jody Cundy and Sarah Storey.

Phil Lane, ParalympicsGB

chief executive, declared himself "delighted" with the selection.

He said: "Britain's cyclists have proved themselves to be among the best in the world by topping the medal table at the 2007 world championships and I look forward to watching them try and replicate this success at Paralympic level this summer."

Rowing, which will be making its first appearance

at a Paralympics, will feature eight British competitors.

Louise Kingsley, GB Paralympic Rowing team manager, said: "Beijing, I'm sure, will be a significant challenge but we are well-prepared and recent training has gone well. We very much look forward to joining the Paralympic Games family."

And 37-year-old David Clarke, a member of *Disability Now's* panel of

experts, who will celebrate his birthday during the Games, said he was "absolutely elated" at his selection for the GB five-a-side blind football squad.

"I have been working toward this moment for the last 14 years and to now know that I have made it is really special," he said.

As *Disability Now* went to press, only fencing and volleyball were yet to announce their squads.



### GB's youngest wheelchair tennis star flips coin in Williams' final

Wheelchair tennis player Jordanne Whiley (*seated*) tossed the coin on centre court ahead of this year's ladies' singles final at Wimbledon. Whiley, 16, was last month selected to be Britain's youngest ever wheelchair tennis Paralympian and will compete at next month's Paralympics in Beijing. She flipped the coin on 5 July to see who would serve first in the match between sisters Serena and Venus Williams.

## Beijing axes second London torch relay

A second torch relay will not be taking place in London after Chinese officials cancelled a Paralympic version due to be held ahead of this year's games.

In a statement, the Beijing Organising

Committee of the Olympic Games (BOCOG) said it had decided to "modify" arrangements for the Paralympic torch relay under the principle of "safe, simple and effective", following the earthquake that hit China in May.

Both the domestic and international legs of the relay have been cancelled.

BOCOG claimed that the

changes were made "to allow the Chinese government to focus on the rescue and relief work", and to "show support" for the people affected by the earthquake.

However, the move also comes after relays for the Olympic Games were marred by protests and disruption from pro-Tibet demonstrators.

Disabled comedian and

activist Francesca Martinez pulled out of the original relay in protest against China's human rights record.

The Beijing 2008 Paralympic torch relay would have been the first ever to include an international element, visiting London, Russia and Canada, along with 16 domestic legs and a route in Hong Kong.

## Q&A: Nathan Milgate

In the eighth and last of our pre-Beijing Paralympics profiles, we question a 21-year-old shooting star



### How did you first get into disability sport?

My next-door neighbour took me along to a shooting club. Fellow shooter Di Coates suggested going along to Disability Target Shooting Great Britain. I shot well, got good coaching and good help and progressed from there.

### What's your biggest sporting achievement so far?

My biggest achievement so far is being selected for Beijing, though I have won a fair few medals in other competitions.

### What's your biggest disappointment in sport so far?

I don't really have any yet.

### What are your ambitions for Beijing and beyond?

It will be a completely new experience for me and I'm

sure it will be an eye opener. I want to shoot as well as I possibly can, obviously. The current training is working out quite well so if I can continue performing the way I am, I'd like to be in with the chance of a medal.

### Who are your sporting heroes?

I just admire people in shooting itself, to see how they've done and how they've progressed.

### Do you think the GB team is in good shape for the Beijing Games and, beyond that, London?

I think so. The team is performing well and training is going well across the board so there is no reason why the whole team can't do well.

### What are your interests away from sport?

Amateur photography. I don't really have time for much else.

# Swimming against the tide

This year's Edinburgh Festival Fringe features a solid line-up of disabled performers, says Kelly Mullan

Did you hear the one about the disability arts reviewer who went to Edinburgh on the wrong year for the bi-annual international disability arts festival? Well, 2008 may be a fallow year for the Degenerate Festival, but the degenerates have spread their mutant seed into the mainstream Fringe, so there's still a fair crop of disabled acts to enjoy.

Liz Bentley and Liz Carr, despite the shared first name and automotive surnames, are not to be confused. Bentley, the "female Ivor Cutler", describes herself as a sit-down comedienne drawing on her personal history of mental health and multiple sclerosis. She'll be swimming, singing songs and telling tales in her show, *Liz Bentley-on-Sea*, at Edinburgh's only poolside venue, Sweet Grassmarket Swimming Pool, from 31 July to 24 August.

Liz Carr was a finalist in the 2006 Funny Women competition, and both the *Hackney Empire* and



*Laughing Horse New Act of the Year* competitions in 2007. From 5 August to 12 August, she'll be part of a rotating line up of six up-and-coming comedians at the Comedy Bank. "Rotating line up" sounds like a rotisserie comedy store, but hopefully the only skewering will be from Carr's piercing wit.

Laurence Clark is the only act this year to reference disability in the title of his

show. In *Spastic Fantastic* at the Pleasance Courtyard from 1 to 10 August, he uses stand-up, hidden camera tricks, and a Superman t-shirt to tell the story of how he attempted to reclaim the contentious S word.

With the tag line, "1978: A gunshot in a crowded bar. A life changed forever,"



American Lynn Manning (pictured above) was a hit at last year's Fringe. Now the award-winning poet, actor, playwright and former world blind judo champion, has returned to Edinburgh with *Weights*, at The Assembly Rooms, from 1 to 25 August.

A red rag to hecklers, Steve Day's show asks *Should I Stay or Should I Go?* His wife says he should quit comedy, but he wants your verdict. Decide his fate at *Laughing Horse*, from 1 to 9 August.

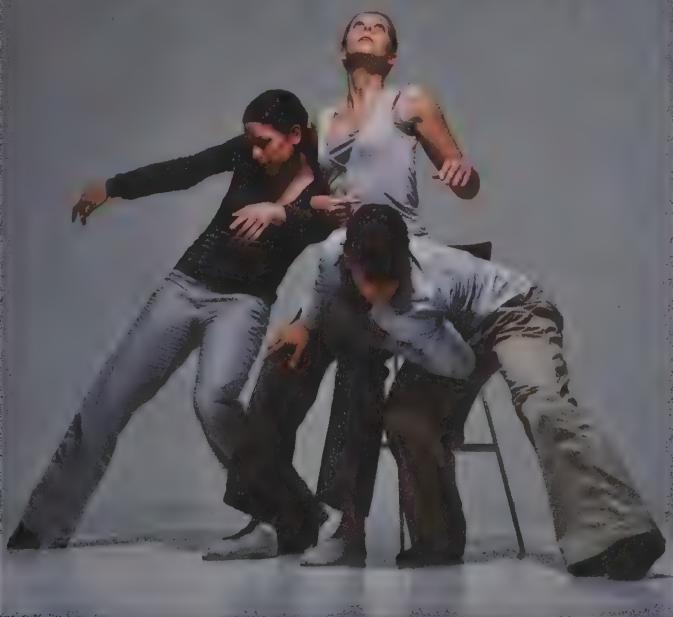
• [www.edfringe.com](http://www.edfringe.com)

## → Up-to-the-minute listings

For all the very latest arts listings visit  
[www.disabilitynow.org.uk/arts](http://www.disabilitynow.org.uk/arts)

## DANCE

# From my bedroom to the Olympics



**From dancing in her bedroom to entertaining 1.5 billion, CandoCo's Victoria Malin tells Kelly Mullan how she made such a balletic leap**

In a first for the Olympics, disabled performers will star in the closing ceremonies of both the Olympic and Paralympic Games. CandoCo, a dance company of disabled and non-disabled dancers, along with dancers from the Royal Ballet and ZooNation, will personify the image London wants to project to the 1.5 billion people watching the

handover of the Olympic flag in the "Bird's Nest", the Beijing National Stadium.

CandoCo's artistic director, Pedro Machado, says: "It's a fair representation of London, in the sense that the way people think here is much more inclusive than any other city. There are still issues around access, things that need to be changed, but London has the right

idea about diversity. When we got invited it felt right and the choreography is similar to what we do in terms of spirit and humour."

Set to strut her stuff in the Nest, CandoCo's Victoria Malin (*pictured centre*) is not about to sing like a bird when gently prodded to reveal plans for the performance. Tight-beaked, she says: "I wouldn't want details to be leaked because then the surprise is gone. I'm very excited and my friends and family are so proud, especially my mum: she's told the whole of Reading!

"I only started dancing three years ago. I've always loved movement but I didn't think dancing professionally was an option. I have CP and I didn't think someone with a disability could do that sort of thing. Dancing was just a personal thing, something I did in my bedroom, until I did some research and discovered CandoCo's foundation course.

"The opportunity to study on the foundation course was amazing. I was pushed and challenged and had lots of one-on-one work with different artists. I got insight into technique and learned to move in different ways, to use my body and work with others."

After graduating from

CandoCo's foundation course, Victoria toured with Blue Eyed Soul Dance Company. While working as a freelance dance and drama teacher, Victoria performed an aerial solo at the Liberty Festival in Trafalgar Square in September 2007.

"Aerial work is incredible. I can do things I can't do on the ground; cartwheels, back-flips. It's so liberating."

Asked what disabled dancers bring to a performance, Victoria says: "When we do unison work, all the dancers doing the same movements, you can see how everyone moves uniquely, yet we can dance together as a company."

On the black cloud of controversy threatening to dampen the Olympic flame, the dancer says: "CandoCo represents the handover of the Olympics to London in 2012. That's why we're there; that's what's important to us."

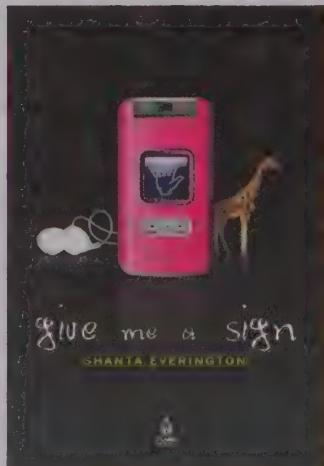
Pedro agrees. "I feel very strongly that we're there representing London and for that I feel good. We're there showing what London is about, so that's a great thing."

- CandoCo will premiere two new pieces on 16 October at The Point, Eastleigh, and will tour across the UK and abroad from October 2008 – December 2009

**BOOKS****GIVE ME A SIGN**

*Give me a Sign* by Shanta Everington is, I guess, a typical book aimed at teenage girls. The story centres around Liz, a young woman of 16, and her life at college, featuring her issues with her mother, bullies and college friends, etc., etc. The one thing not typical of the teen novel is Doug.

Doug starts out as Liz's object of affection and then they have a relationship. As well as being gorgeous, Doug is



deaf, unlike anyone before in Liz's world. So Liz's life starts to change as she spends time with Doug, finding herself in the world

of deaf culture and BSL classes, which brings her greater self-esteem because for once she is happy. It is a bittersweet story of first love, with a disability twist.

There are some parts (like Liz stuffing cotton wool in her ears to understand what it's like to be deaf) that will get up the noses of the very political. The author tries to introduce Liz to deaf culture (for me the jury is out on how well this is done). What I find very interesting is that we are given a chance to view disability through the eyes

of a non-disabled partner. In some ways, I want to excuse her ignorance, but I wanted to explore the idea of deaf culture deeper.

I would recommend this book to the young (perhaps not the very young, because of the references to sex!) and the young at heart, but you should look elsewhere for a really strong message about deaf culture.

**Kate Caryer**

- *Give me a Sign* by Shanta Everington; Flame Books; £6.50; ISBN: 978-0-9556725-2-1

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# webwatch



Comedian **Steve Day** has a good return from thousands of hours on Facebook: one gig booking and one lost friend

Internet? Nah, never use it.

Except all the time. I log on to **Facebook** for five minutes at half past eleven and the next thing I know it's two am. As I look back over the time I have spent there, I can at least take comfort in what I've achieved in the last 14-and-a-half-hours. Nothing.

I did once get a gig booking from Facebook, so the 11,000 man-hours haven't all been wasted. I was on **MySpace** a lot, too, but it feels like the club that no-one goes to any more. In fact, Facebook caused me to fall out with my best friend, Chris McCauseland, who like me is a comic. He's

blind, though, so we've got to be friends for that one reason because we're always put on the same bill together. People think, ooh, we've got the blind bloke, let's get the deaf bloke, see the synergy we could make there! What they really want is the Special Olympics of comedy, "The Aren't They Marvellous Show".

"Aw! Look at the way they're coming up, trying to make us laugh!"

"They're just like people when they do that, aren't they?"

This has gone on for the last five years and in all that time I've never heard him and he's never seen me.

I've fallen out with Chris because of the top friends thing on MySpace. You can have 52 top friends, but what is the point of being somebody's 51st best friend? So I've cut mine down to eight. The problem, though, is that when you get a new friend and want to put them in your top eight, somebody close to you has got to go.

You don't get that problem on **Bebo**, though, because someone there is quite likely to have committed suicide and you've always got a vacancy, but on MySpace it's a problem. I had a new friend, far better looking than my ugly mugs. What was I going to do? Then I thought: I know what I'll do, I'll get rid of Chris. He's blind, he'll never know.

Two hours later he sends me an email demanding to know what he's done wrong.

Turns out he's got some paranoid blind person's software thing, reporting it all back to him in a voice.

Anyway, the internet. I'm a big one for the online

papers. The **Guardian** and the **Telegraph** are best for lily-livered liberalism and pedantically-detailed reports of neighbourly disputes over shared driveways gone tragic respectively.

**sportinglife.com** keeps me up to date with sports I'm most often watching on TV at the same time. I use **Digital Spy** to find out what happens in the soaps so I don't have to actually watch them but can spoil them for my wife.

"He dies, doesn't he?" being one of my favourite lines.

**YouTube** passes me by, due to lack of subtitles. Maybe one day. Same too for the BBC iPlayer. I long for a repeat of Ann Widdecombe on the news saying, "Let me give you an analogy," which came up on the subtitles as, "Let me give you anal joy."

Sorry, I have to go, an event of great importance has occurred. Someone has requested on Facebook that I complete a questionnaire about my favourite ways to be romantic whilst skiing. Bye...

## → Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)
- phone us 020 7619 7323

# worklife

# A coach ticket

**Danny West**, principal consultant and coach of RYL Training and Coaching Consultancy, describes how dealing with the challenges of being diagnosed with HIV led to a career in life coaching

In 1985, at the start of a bright new career in social work, I was one of the first people in the UK to be diagnosed HIV positive, which at that time meant a life expectancy of 18 months to two years.

I soon realised I needed to deal with my stress levels, so I retired on medical grounds and set about managing my health condition and responding to the many barriers and challenges of HIV.

In 2006, after 14 years of ill health and life on incapacity benefit, I set up my own training and coaching consultancy in

**Coaching helps you achieve your goals in health, relationships, work, finances and leisure**

south-east London. Being self-employed enabled me to work at my own pace, rest when necessary and manage my health condition without fear of prejudice or



Danny works with businesswoman Steph Cutler at a coaching event for visually-impaired people

scrutiny from an employer.

The former United Kingdom Coalition of People Living with HIV found me a coach who empowered me and enabled me to develop my business idea. I soon realised that coaching was the ideal tool to support disabled people to achieve their personal and professional goals, and in early 2007, I secured a scholarship from The Coaching Academy, Europe's largest coaching training organisation, which allowed me to complete a personal performance coaching diploma.

There are many stigma-associated barriers faced by people living with HIV and

there are many associated health-related conditions that can lead to impairments. Coaching, however, gives me complete autonomy over my working life. I can work from home and provide coaching by telephone or email, and determine how much work I do.

## DANNY WEST: CAREER PATH

- 1977: Left Northumberland Park school in north London with four CSEs
- 1979: First residential social worker position
- 1984: First managerial social work position
- 1985: Diagnosed with HIV
- 1986: Freelance trainer
- 1989: Appointed first local government training officer for HIV in the UK
- 1992: Freelance trainer
- 1995–2006: Managing health condition
- 2006: Established training and coaching consultancy
- 2008: Gained coaching diploma

Coaching is incredibly rewarding, especially when clients grow and achieve their goals, and I am inspired by the many successes of people I have worked with.

So what is personal performance coaching? It helps you achieve your goals in health, relationships, work, finances and leisure through a confidential relationship with your coach. Coaching doesn't focus upon past failures, disappointments or mistakes or on what you can't do but on what you can do, developing your self-confidence and self-esteem.

If you enjoy working with people and have a positive, empowered and determined outlook on life, especially in relation to the many barriers associated with having a disability or long-term health condition, I would recommend a part- or full-time career in coaching. There are many online coaching resources books and training courses.

• [ryl-training-consultancy.co.uk](http://ryl-training-consultancy.co.uk)

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Cont'd see pg 74

# GRAEae THEATRE COMPANY

Our current Chair completes his term later this year. We are now seeking a new person to lead our Board of Directors, senior management and staff. Working closely with our joint Chief Executives, the Chair will assist in ensuring that Graeae meets its organisational objectives and artistic ambition.

## Interested?

We are now seeking a disabled or D/deaf person to take on the role of Chair for a fixed period of three years. The new Chair should have senior leadership experience and qualities necessary to undertake a role that will involve work both in London and across the UK along with the empathy and sensitivity necessary to accept and promote the fundamental principles of Graeae; innovative disability theatre and the true inclusion of disabled people in the arts.

The successful candidate will have the time, energy and commitment to get to know Graeae and be jointly responsible for the implementation of our new business plan, move to new premises and the recruitment of further trustees and advisors as required.

The post is unremunerated, but all travel, access and reasonable expenses will be reimbursed. Professional development, coaching and mentor support is available to the successful candidate. Graeae is committed to equality and diversity.

**Closing Date: 31 August 2008.** Please visit our website – [www.graeae.org](http://www.graeae.org)

For further information and recruitment pack please contact: Steve Mannix, Acting Chair, [steve@graeae.org](mailto:steve@graeae.org)

# is seeking a new Chair

A Company that refuses to be relegated to the sidelines  
*The Guardian*

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Mobilise Headquarters, Ashwellthorpe Hall Drive, Ashwellthorpe, Norwich NR16 1EX.

Tel: **01508 489449**. Email: **officemanager@mobilise.info**

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September published 30 August. Classified deadlines: Booking: 11 August. Copy: 13 August.

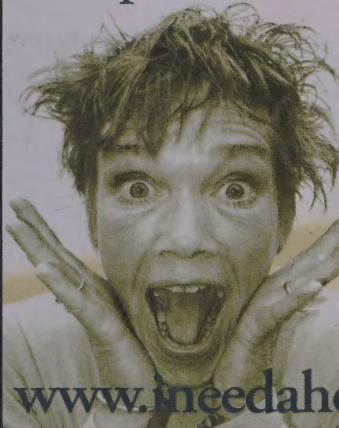
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# backlash



## It wasn't me. Blame my doppelganger

The thought of running a marathon makes me turn green, says **Paul Carter**. But not as green as the wristband they made him wear at a music festival

I've just got back from a music festival, where I was given a delightful wristband to wear so I could get onto the viewing platform. Now, this wasn't any normal wristband. Not like one of those simple white ones made out of sticky paper. Oh no, this one was special. It was luminous green, and said DISABLED on it in massive, purple, screaming letters, which amused me greatly. I'd never been branded before.

Now, making me wear a wristband to identify me as a bona-fide, paid-up member of the disableds is surely a bit like making Amy Winehouse wear a chuffing-enormous-packet-of-fags-shaped badge to show people that she likes the occasional

**“I am more likely to be cast as the next Incredible Hulk than I am ever even to consider running a marathon”**

smoke and the odd drink. Being as obviously disabled as me does have its benefits, but it can sometimes be a bit rubbish being so



UNIVERSAL PICTURES

recognisable. It means I can't get away from people I can't be bothered to talk to, or blend into the background inconspicuously. I'd be a really *rubbish* spy.

It also means that I get recognised by everyone I've ever met in my entire life ever, no matter how long ago it was, or how inconsequential the circumstances. The more random the better, in fact, as they always tend to open with the infuriating, “do you remember me?” It puts the ball embarrassingly in my court and sets the conversation off on the path of being like a really crap game of Guess Who?

“It's Marjorie! I used to see you with your mum on the number 16 bus every second Tuesday morning in 1984. Do you remember?”

That kind of thing. It may not sound annoying, but my mum knew a lot of Marjories. And I evidently had an infinite number of nursery teachers.

What I find very weird, though, is when people mistake me for other people. A man stopped me in the street one day and happily told me how he'd seen me “doing the marathon” on TV the week before.

Before I continue, I should clarify that I have never run a marathon in my life, or participated in any activity that could possibly be construed as a marathon. I am more likely to be cast as the next Incredible Hulk than I am ever even to consider running a marathon.

“It was definitely you!” he

said indignantly, after I'd laughed at the very suggestion, as if I'd somehow absent-mindedly forgotten the fact I'd slogged 26 miles the day before. Idiot.

Another man (it's always men, sadly) at Oxford Circus tube asked me if my name used to be John, and when I said no, he looked dead puzzled and muttered that I was a “dead spit” as he walked away.

It got me thinking that maybe there's a doppelganger no-armed-no-legged-bloke clomping around central London. If there is, just remember, the next time you see someone similar staggering past your house at 3am, obstructing traffic and walking into lampposts, it's not me. It's definitely the other guy.



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